

**An Exploration of the Lived Experience of Progressive  
Cerebellar Ataxia: an Interpretative Phenomenological Analysis**

**A thesis submitted for the degree of Doctor of Philosophy**

**By**

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## **Abstract**

### **Background and Purpose**

Progressive cerebellar ataxia is a rare neurological condition characterised by uncoordinated movement, and impaired speech articulation. Rehabilitation and physiotherapy in particular, form the cornerstone of healthcare intervention. Little qualitative research has been undertaken to understand the subjective experience of this complex condition. This study explored the experience of progressive cerebellar ataxia, physiotherapy and physiotherapy services from the perspective of people living with this condition.

### **Method**

Interpretative Phenomenological Analysis underpinned this inductive qualitative enquiry. Twelve people with a progressive cerebellar ataxia participated in semi-structured interviews. All participants had some experience of physiotherapy. Interviews were transcribed. A case by case idiographic analysis was undertaken followed by a cross case analysis.

### **Findings**

Five super-ordinate themes were identified. 'The embodied experience of progressive cerebellar ataxia' emphasised the foregrounding of the body, and the disruption of the skilful interaction between body and world. 'Identity, stigma and disrupted embodiment in public spaces and places' encapsulated how participants made sense of actual and perceived stigma and discrimination. 'Lifeworld meets biomedicine: a complex juxtaposition' described participants' problematic relationships with healthcare practitioners and their disease-centric world. 'Wresting control in the face of uncertain and changing forces' portrayed participants' attempts to understand and reinterpret their condition on their own terms. 'Exercise: a multifaceted contributor to managing life with ataxia' captured the meaning of exercise and physical activity.

One over-arching theme, 'Retaining a homelike way of being-in-the-world', cautiously indicated that whilst participants described 'unhomelike' lifeworlds (uncomfortable and disturbing); they simultaneously held onto, and sometimes realised, the possibility of 'homecoming', for example through the generation of new modes of belonging.

### **Conclusion**

This study provided a detailed, phenomenological account of the lived experience of progressive cerebellar ataxia. New insights were developed that have the capacity to inform not only physiotherapy practice but also other healthcare disciplines. New avenues for future research were also identified.

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## **List of Abbreviations**

**DH:** Department of Health

**DNA:** Deoxyribonucleic acid

**FRA:** Friedreich's ataxia

**GP:** General Practitioner

**HD:** Huntington's disease

**HIV:** Human immunodeficiency virus

**HQ:** Head quarters

**IPA:** Interpretative phenomenological analysis

**MJD:** Machado-Joseph disease

**MS:** Multiple sclerosis

**NHS:** National Health Service

**PD:** Parkinson's disease

**SCA:** Spinocerebellar ataxia

**UK:** United Kingdom

**US:** United States of America

The following notation is used in the text for references published originally in a foreign language, followed by an English translation, e.g. Heidegger (1962 [1927]), where 1962 refers to the English translation used in this thesis and [1927] refers to the original date of publication in German.

The following notation is used for direct quotations from participants in this study to indicate a pause; ..., or words that have been omitted because they were not relevant or for maintaining anonymity; [...].

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## **Chapter 1**

### **Introduction**

Progressive cerebellar ataxia is a rare neurological condition for which there is no effective disease-modifying intervention (Finsterer, 2009; Klockgether, 2011). Unlike other neurological conditions such as multiple sclerosis and stroke, little qualitative enquiry has been undertaken to understand the subjective experience of this complex condition. Physiotherapy is one of the rehabilitation options offered to people living with ataxia, but physiotherapists have limited high quality evidence on which to base their interventions (Martin et al. 2009). Using Interpretative Phenomenological Analysis (Smith et al. 2009), this study explored the experience of progressive cerebellar ataxia, physiotherapy and physiotherapy services from the perspective of people who live with this condition. By investigating a topic largely neglected by previous researchers, and by identifying key insights about the meaning of cerebellar ataxia and its impact on the everyday lives of people living with this condition, this study offers a distinct and original contribution to knowledge in this field. The academic value of this work rests in providing empirical data that supports, questions and extends current theorising about the experience of long-term illness. It is further argued that the findings of this type of enquiry may help healthcare practitioners, such as physiotherapists, more effectively address the concerns and priorities of the people who seek their advice and support.

### **1.1 Ataxia**

Ataxia, meaning dis-order, is characterised by incoordination of the limbs and trunk, dysarthric speech (impaired clarity and intelligibility), dysphagia (swallow dysfunction) and oculomotor dysfunction e.g. double vision, dizziness (Ghez and Thach, 2000; Marsden and Harris, 2011). Ataxic motor behaviour is typified by errors in the planning and execution of voluntary action, specifically the direction, amplitude, force, timing and velocity of movement (Ghez and Thach, 2000). People living with ataxia have difficulty adjusting movement in time and space, and adapting to novel or complex environments (Morton and Bastian, 2006). All activities of daily living such as talking, reaching and walking are affected. Unsteadiness and slurred speech often make it appear as if the person with ataxia is drunk (Rothwell, 1994). Non-motor features, in particular cognitive impairments (such as working memory and visuospatial processing), are also beginning to be understood as part of the clinical picture, but further work is required to detect the mechanisms involved and to identify the specific deficits (Strick et al. 2009; Timmann and Daum, 2010; O'Halloran et al. 2012).

Ataxia is caused by a variety of pathologies associated with either degeneration or destruction of parts of the cerebellum and/or its connections with other parts of the central nervous system (Ghez and Thach, 2000; Marsden and Harris, 2011). Much remains to be understood about the function of the cerebellum but there is broad agreement that it plays a crucial role in the adaptive control of motor behaviour (Rothwell, 1994; Ghez and Thach, 2000; Strick et al. 2009). Put simply, the cerebellum is thought to work subconsciously to compare general motor commands (rough blueprints for action) from higher brain centres, with feedback about external (environmental) conditions and internal feedback about, for example, the position of the limbs and trunk in space. By comparing intended action with real world conditions (internal and external), the cerebellum detects errors in the motor plan and indirectly generates corrective signals. This fine-tuning adjusts motor activity so that it matches external conditions (Rothwell, 1994; Ghez and Thach, 2000). The detailed co-ordination and execution of action is therefore left to the cerebellum, sparing higher level control and cognitive effort for other functions (Ghez, 1991). For example, when reaching for a cup the general motor command for reach and grasp is generated by the higher brain centres. Using feedback from the environment (e.g. the size, shape and anticipated weight of the cup) and internal feedback (e.g. the position of the arm in space), the cerebellum is thought to predict and then, through its connections to motor centres in the central nervous system, adjust the direction, amplitude, force, timing and velocity of the basic reach and grasp movement pattern, as well as background postural activity, to produce an accurate and efficient functional action.

Disruption of the cerebellar pathways or processing centres that normally detect and correct movement errors, and respond to unanticipated perturbations, is thought to underlie the inaccurate, inefficient and uncoordinated movement typically observed in people living with cerebellar ataxia (Marsden and Harris, 2011). As a result of cerebellar dysfunction, the sophisticated processing that normally occurs subconsciously moves into the conscious realm where only a rough and effortful approximation of the cerebellum's role can be undertaken (Ghez, 1991). As chapters 2 and 3 will demonstrate, very little research has been undertaken to understand what it might be like to live with this sort of disordered movement. One of the earliest insights was provided by a patient of the neurologist Gordon Holmes in the 1930s. The following quotation appeared as the only reference to the personal experience of cerebellar ataxia in a paper otherwise wholly concerned with understanding the role of the cerebellum in motor control:

'The movements of my left arm are done subconsciously, but I have to think about each movement of the right [affected] arm. I come to a dead stop in turning and have to think before I start again.' (Holmes, 1939:22)

This person's taken-for-granted ways of carrying out his everyday activities seem to have been disrupted following injury to his cerebellum. What would normally be experienced as fluid, automatic and uninterrupted activity, he perceived as deliberate and fragmented, dependent upon concentrated effort. Insights of this type, grounded as they are in a person's account of their everyday life, may help healthcare practitioners such as physiotherapists develop a deeper understanding of the difficulties faced by people living with cerebellar ataxia. However, in 2006, when the present study was in the early stages of development, this sort of enquiry and its potential contribution to practice was largely overlooked by both clinicians and researchers.

### **1.1.1 Progressive Cerebellar Ataxia**

Ataxia may present as a symptom of several neurological conditions such as multiple sclerosis, posterior fossa tumour, stroke, and brain injury (Ghez, 1991; Marsden and Harris, 2011). However, the term "progressive cerebellar ataxia" is used to describe a complex group of ataxia-dominant, neurodegenerative disorders that are distinct from other neurological conditions (Wardle and Robertson, 2007; Klockgether, 2011). It is the experience of this type of ataxia, rather than the experience of ataxia as an epiphenomenon of another condition, that forms the focus of this study.

The precise number of progressive cerebellar ataxias is unknown but Klockgether (2011) estimated that there were between 50 to 100 different ataxias, each with a specific genetic or molecular cause. Classification of the progressive ataxias remains imprecise but three main subgroups are currently identified (Klockgether, 2011); first, the hereditary ataxias (Friedreich's ataxia (FRA); the spinocerebellar ataxias (SCA), episodic ataxia and other rare types of heredoataxias), second, the non-hereditary degenerative ataxias (synonymous with sporadic or idiopathic), and finally, the acquired ataxias (e.g. ataxias due to vitamin deficiency or alcoholic degeneration). The acquired ataxias generally have a known cause and may be treatable in ways that the other progressive ataxias are not. As they are more treatable, these ataxias may be experienced differently from the hereditary and non-hereditary ataxias and therefore they are not the focus of the present study. A summary of the main clinical features of the progressive cerebellar ataxias is presented in Table 1.1.

**Table 1.1 Clinical Features of the Progressive Cerebellar Ataxias**

Hereditary Ataxias			Idiopathic Ataxias
Friedreich's Ataxia	Spinocerebellar Ataxias	Episodic Ataxias	
<ul style="list-style-type: none"> <li>Progressive gait, limb and trunk ataxia</li> </ul>	<ul style="list-style-type: none"> <li>Slowly progressive ataxia</li> </ul>	<ul style="list-style-type: none"> <li>Discrete episodes, minutes, hours, days</li> </ul>	<ul style="list-style-type: none"> <li>No genetic or other known cause</li> </ul>
<ul style="list-style-type: none"> <li>Dysarthria</li> </ul>	<ul style="list-style-type: none"> <li>Retinopathy</li> </ul>	<ul style="list-style-type: none"> <li>Ataxia</li> </ul>	<ul style="list-style-type: none"> <li>Ataxia of gait and stance</li> </ul>
<ul style="list-style-type: none"> <li>Sensorimotor neuropathy</li> </ul>	<ul style="list-style-type: none"> <li>Neuropathy</li> </ul>	<ul style="list-style-type: none"> <li>Vertigo</li> </ul>	<ul style="list-style-type: none"> <li>Peripheral nervous system involvement</li> </ul>
<ul style="list-style-type: none"> <li>Absent deep tendon reflexes</li> </ul>	<ul style="list-style-type: none"> <li>Spasticity</li> </ul>	<ul style="list-style-type: none"> <li>Dizziness</li> </ul>	<ul style="list-style-type: none"> <li>Posterior column involvement (sensory)</li> </ul>
<ul style="list-style-type: none"> <li>Loss of proprioception and vibration sense</li> </ul>	<ul style="list-style-type: none"> <li>Dyskinesia, dystonia, myoclonus, chorea</li> </ul>		<ul style="list-style-type: none"> <li>Pyramidal tract involvement (motor)</li> </ul>
Other features: <ul style="list-style-type: none"> <li>Hypertrophic cardiomyopathy</li> <li>Diabetes</li> <li>Sleep breathing disorders</li> </ul>	Other features: <ul style="list-style-type: none"> <li>Sleep disorders</li> <li>Fatigue</li> </ul>		

(Data sourced from; Abele et al. 2002; Fogel and Perlman, 2007; Wardle and Robertson, 2007; López-Bastida et al. 2008; Finsterer, 2009; Pedroso et al. 2010; Brusse et al. 2011; Klockgether, 2011; van Gaalen et al. 2011)

The progressive ataxias are categorised as rare diseases because, taken as a whole, the prevalence is less than 50/100,000 (European Commission, 2008). Prevalence estimates for the progressive ataxias vary across countries and continents (Finsterer, 2009). Craig et al. (2004) estimated the minimum prevalence of an autosomal dominant cerebellar ataxia (SCA6) in the northeast of England as 8/100,000. Muzaimi et al. (2004) estimated an amalgamated prevalence for idiopathic, SCA6, FRA and episodic progressive ataxias for southeast Wales as 10.2/100,000. Taken together, these UK specific data (Craig et al. 2004 and Muzaimi et al. 2004) suggested that the progressive cerebellar ataxias, whilst rare, may be more prevalent than other well-known neurological conditions. For example, Muzaimi et al. (2004) argued that the prevalence of autosomal dominant cerebellar ataxias were more common than conditions such as motor neurone disease (6.2/100,000) and Huntingdon's disease (6.4/100,000). Wardle and Robertson (2007) and Klockgether (2011) argued similarly, and suggested that the prevalence of progressive late-onset cerebellar ataxia (hereditary and idiopathic) was previously underestimated.

Uncertainty often dominates the diagnostic and genetic testing process, as well as the inheritance patterns, of these complex conditions (Schöls et al. 2004; Wardle and Robertson, 2007). Furthermore, accurate prognosis regarding life expectancy and

disability is difficult to predict at an individual level because insufficient longitudinal studies have been conducted (Whaley et al. 2011). Genetic testing is only available for the specific diagnosis of some of the progressive ataxias (Schöls et al. 2004), and although critical to diagnosis, definitive results may not be available in 50-80% of referred cases (Wardle and Robertson, 2007; Finsterer, 2009; Klockgether, 2011). Not all genetic tests are available routinely, and testing may require collaboration with specialist or research laboratories (Finsterer, 2009).

Many adults presenting with the signs and symptoms of a progressive ataxia where a genetic cause cannot be found are generally diagnosed with idiopathic (sporadic) progressive cerebellar ataxia (Klockgether, 2011). In these cases, whilst the underlying condition may be hereditary, no tests are available that can identify the specific genetic disorder to provide a definitive diagnosis (Abele et al. 2002). Also diagnoses are subject to change once the full range of symptoms emerge e.g. in FRA an incorrect diagnosis of idiopathic progressive cerebellar ataxia is often given (Dürr et al. 1996). Similarly, an initial diagnosis of episodic ataxia may be later adjusted to probable or possible FRA or multiple systems atrophy (Wardle and Robertson, 2007).

More than 25 different SCAs have been genetically defined (SCA 1, SCA2, SCA3 etc.) and causative mutations have been identified in 19 of them (Klockgether, 2011). One of the main features of the spinocerebellar ataxias is the phenomenon of anticipation. This genetic trait results in a pattern of inheritance characterised by earlier onset in subsequent generations, more severe symptoms and rapid progression (Friedman, 2011). This feature is particularly prominent in SCA7 where, in extreme cases, affected children may die before an affected grandparent becomes symptomatic (Honti and Vécsei, 2005; Manto, 2005). For SCAs where the underlying genetic mutation is known and where anticipation is likely, precise prediction for age of onset and severity cannot be given, rendering genetic counselling particularly difficult (Schöls et al. 2004).

Therefore, whilst progressive cerebellar ataxia poses high levels of disability and uncertainty similar to conditions such as multiple sclerosis, it also carries a genetic component that sets it apart from these conditions, as well as other genetic conditions that have a more straightforward inheritance pattern. Progressive cerebellar ataxia may therefore be experienced differently from many other neurological conditions. Qualitative research that remains open to the ways in which these factors may interact and shape the subjective experience, may illuminate particular issues that deepen the understanding of what it is like to live with this condition. This study, by articulating the details of this understanding, and by laying out the evidence on which it is based, may

encourage not only physiotherapists but other healthcare practitioners to re-examine tacit preconceptions and assumptions about their practice. This new knowledge might then be used to tailor practice towards the issues that most concern people living with progressive cerebellar ataxia.

### **1.1.2 Medical Treatment and Intervention**

No effective disease modifying or other pharmacological treatments have been developed which can reverse or cure progressive cerebellar ataxia (Finsterer, 2009; Klockgether, 2011). Symptomatic treatments such as acetazolamide have been found to reduce the severity and frequency of attacks in episodic ataxia (Jen, 2008), and antioxidants such as idebenone, CoQ10 and vitamin E have been shown to improve cardiac function, speech and mobility for people with Friedreich's ataxia (Hart et al. 2005). However, a phase 3 double-blind, placebo-controlled trial of idebenone failed to demonstrate efficacy in FRA (Lynch et al. 2010). Research is on-going and the development of effective therapies in the near future seems possible (Finsterer, 2009). In the meantime, rehabilitation (occupational therapy, physiotherapy and speech and language therapy) remains the cornerstone of what is offered for people living with progressive ataxia (Ataxia UK, 2009; Whaley et al. 2011). Physiotherapy, as one of these rehabilitation options, is generally understood as having a supporting role for people living with long term health conditions. Physiotherapists, for example, aim to work in partnership with patients by helping to restore, maintain or improve function and movement, and to have a positive effect on quality of life (Chartered Society of Physiotherapy, 2012). However, without further research to explore what physiotherapy means to people living with progressive cerebellar ataxia, it is unclear what shape this supportive role should take and how it might best work over time.

## **1.2 Exploring the Contexts Underlying the Development of the Research**

### **Questions**

Evidence based practice forms the foundation of modern physiotherapy (Ritchie, 2001) and is generally considered to consist of integrating the best research evidence with clinical expertise, together with individual patient preference derived from patient-centred research (Sackett et al. 1996). The researcher was aware from her own practice, as a physiotherapist, and from anecdotal reports, that the evidence of effectiveness for rehabilitation interventions for people with a progressive cerebellar ataxia was sparse. In 2006, when the present study was in the early stages of

development, informal discussions with colleagues and rehabilitation practitioners, and a preliminary examination of the literature, suggested that the progressive cerebellar ataxias were under-researched, both from a qualitative and quantitative perspective, and as such there was little in the literature to guide clinical practice.

From a quantitative perspective, three reviews of the literature (including one by the author), published whilst the present study was in progress, demonstrated a lack of high quality rehabilitation research for progressive cerebellar ataxia (Cassidy et al. 2009; Martin et al. 2009; Marsden and Harris, 2011). There was some evidence that physiotherapy had modest effects on gait and trunk control, but as the majority of participants in these studies experienced ataxia as part of another condition (such as multiple sclerosis, brain injury or cerebellar stroke), the extent to which the findings from previous research could be extrapolated to people living with a progressive cerebellar ataxia was limited.

As chapter 3 will demonstrate, little qualitative research has been undertaken with people living with cerebellar ataxia in order to understand their experiences and priorities, and how they manage ataxia in their everyday lives. In 2006, this lack of research represented a significant gap in the literature. This was especially so as the focus of Department of Health (DH) policies at the time emphasised the importance of patient-centred care, the biopsychosocial model and the re-configuration of services in ways which met the needs, expectations and concerns of people living with long term conditions (DoH, 2005, 2007; Chartered Society of Physiotherapy, 2005; Tompkins and Collins, 2006). Although it could be argued that people living with progressive cerebellar ataxia might be expected to experience their condition and healthcare services in similar ways to people living with other progressive neurological conditions, it was also possible, as argued above, that this might not be the case. Progressive cerebellar ataxia perhaps has more in common with Huntington's disease, a rare, genetic and progressive neurological condition (Bertram and Tanzi, 2005), than with more well-known and more extensively researched conditions such as multiple sclerosis, Parkinson's disease and stroke. Therefore, whilst it is possible that people living with progressive cerebellar ataxia may share some concerns and experiences with people living with other progressive neurological conditions, there may also be unique and nuanced perspectives that have yet to come to light.

Looking at rehabilitation for people with progressive cerebellar ataxia through the lens of evidence based practice suggested an urgent need for further research to be undertaken in this field. Several avenues, quantitative or qualitative, seemed to be open.

However, whilst the application of findings from both qualitative and quantitative research may contribute to well-being, and add to the evidence underlying rehabilitation practice, Hammell and Carpenter (2004) argued that quantitative rehabilitation research often focused on esoteric problems which had little relevance for practitioners, and failed to connect with, or address the real world concerns of, people living with particular conditions. For this researcher, the lack of qualitative work which sought to understand the lived experience of cerebellar ataxia formed the most significant gap in the evidence. For these reasons, and at this early stage in the development of rehabilitation research in this field, new work that aimed to understand the day to day concerns, priorities and experiences of people living with ataxia (including their experience of physiotherapy) seemed to claim precedence over the development of intervention studies and resonated most strongly with the interests and motivations of the researcher. This rationale matured following informal meetings where the preliminary aims of the present study were outlined and discussed with people living with progressive cerebellar ataxia.

### **1.3 Reflexivity: Explicating the Position and Influence of the Researcher in the Research**

Reflexivity is seen as an important part of all phenomenological research (Finlay, 2011). The reflexive stance taken towards this study resonates not only with Finlay's (2003a) and Shaw's (2010) concept of hermeneutic reflection but also the reflexive attitude embedded within the hermeneutic circle (Smith, 2007; Smith et al. 2009). Hermeneutic reflection is a process of self-examination with respect to interpreting, understanding and explicating the position and influence of the researcher in the research (Shaw, 2010). Ultimately this process should revise the researcher's pre-conceptions about the phenomenon under investigation, as well as the initial orientations of the research itself, so that the phenomenon can be understood, as far as is possible, in its own terms (Finlay, 2003a). Whilst Interpretative Phenomenological Analysis (IPA) constitutes the bracketing of prior experiences within the model of the hermeneutic circle rather than as a separate process within phenomenological enquiry (Smith et al. 2009), the stance taken towards reflexivity in IPA still has much in common with the model of hermeneutic reflection described by Finlay (2003a) and Shaw (2010).

To briefly explain, the hermeneutic circle refers to a cyclical, rather than linear, process of interpretation. The analytic focus is on the participant's sense making, rather than the researcher's preconceptions (Smith et al. 2009). As described by Smith (2007), the researcher starts at one side of the circle, attentive only to his or her own biography and

personal understanding of the phenomenon under investigation. The participant is on the other side of the circle, fully involved in his or her own world of experience. Before moving around the circle to encounter the participant, the researcher attempts to set aside or 'bracket' (Smith 2007:6), or at least to become more aware of, his or her preconceptions in order to adopt an attitude of sensitivity, flexibility and 'thoughtful vigilance' towards the research participant's sense making, particularly the unpredicted and the unexpected (Dahlberg et al. 2008:97). After engaging with the research participant, the researcher returns to the other side of the circle, 'irretrievably changed because of the encounter' to continue the interpretative process (Smith, 2007:6). As a result of the journey round the hermeneutic circle, the researcher is prompted to look at and understand the phenomenon in a new light. This openness towards the data changes the way in which the researcher understands the full picture, and the role played by his or her prior conceptions in interpreting the data. Motivated by new insight, the researcher is inspired to undertake a further iterative exploration of the text (Smith et al. 2009). A more in-depth explanation is provided in chapter 4, Methodology.

Considered together, it would seem that hermeneutic reflection (Finlay, 2003a; Shaw, 2010) and IPA's explication of the concept of the hermeneutic circle seem to share critical features that mark them out as providing compatible models for understanding the impact of the researcher on the research. For these reasons, both these models were adopted as the theoretical underpinning of the reflexive stance undertaken in the present study. Consistent with this approach, critical examples of this process are embedded within the thesis to illustrate how reflexivity was used in the context of this study.

### **1.3.1 Initial Reflexive Statement**

As reflexivity involves critical self-examination this section is written in the first person. At the start of this study, I was unaware how my physiotherapy background (as practitioner and lecturer) might have affected the direction, development, and findings of this study. Consistent with the phenomenological approach, I used a reflective diary to increase self-awareness (Finlay, 2003a). I recorded, as far as possible, my thoughts, anxieties, questions and experiences in order to understand how my views as a physiotherapist in particular, and a novice qualitative researcher in general, may have shaped data collection and analysis. At the start of this study I was firstly concerned and preoccupied with my obvious lack of psychology training and the influence this may have on the research. Second, these concerns led me to initially reject data that I interpreted as in any way relating to biomedicine or motor impairment. To me, this sort of data could not

be considered phenomenologically interesting, partly because ataxia related impairments were well explained in biomedical terms and also because I was unable to see how participants' descriptions of these impairments would add to the understanding of the lived experience of cerebellar ataxia. Critical self-reflection and in-depth engagement with the data reconstituted these naïve preconceptions. Examples of this process are described in more detail in chapter 5 (Methods) and chapter 6 (the first findings chapter). At the early stages of the research process I was less able to examine or identify, exploit or critique other tacit assumptions and influences. These prejudices and orientations were only worked out during the analysis and writing up of the present study through the process of hermeneutic reflection (Finlay, 2003a; Shaw, 2010) and, in phenomenological terms, with respect to "the things themselves" (Husserl, 1970 [1900/1901]:252). These issues are considered in more depth in chapter 11 (Discussion).

#### **1.4 Research Questions**

This study explored how people living with a progressive cerebellar ataxia made sense of their condition in the context of their everyday lives and how they perceived physiotherapy and physiotherapy services. With respect to these interests, the following research questions were formulated and are further defended in the literature review (chapters 2 and 3):

1. What is the meaning of progressive cerebellar ataxia for people who live with this condition?
2. How do people living with a progressive cerebellar ataxia experience healthcare, and physiotherapy in particular?
3. What is the meaning of exercise and activity participation for people living with progressive cerebellar ataxia?

#### **1.5 Overview of the Thesis**

The purpose of this thesis is to contribute to an improved understanding of progressive cerebellar ataxia by undertaking an in-depth exploration and analysis of the experiences of people living with this condition. This overview briefly describes each chapter and orientates the reader to the ways in which the thesis is organised.

**Chapter 1** established that the progressive cerebellar ataxias are rare, long term, degenerative conditions associated with particular impairments and healthcare experiences that are worthy of further investigation. This chapter offered a background context to the development of the research questions. It identified why the experience of cerebellar ataxia may differ from other progressive long term neurological conditions, and, by doing so, it exposed a gap in understanding, and made a case for undertaking a qualitative exploration of the subjective experience of this condition. The contexts in which this study was undertaken were introduced. The approaches taken by the researcher with respect to reflexivity were addressed and potential analytic issues were foregrounded.

**Chapter 2** reviews the literature concerned with understanding the subjective experience of chronic illness and identifies the ways in which the findings from this extensive body of work were used to inform a sensitive exploratory enquiry into the experiences of people living with ataxia. Furthermore, it is argued that the exploration of the subjective experience of cerebellar ataxia is capable of making a unique contribution to this field. This chapter also makes sense of the different theoretical threads informing the academic understanding of long-term illness, and makes a case for undertaking a phenomenologically informed enquiry.

**Chapter 3** presents a critical review of literature focussing on understanding progressive cerebellar ataxia from the perspectives of people living with this condition. Key emerging themes from this body of work are identified and the need for further research in this field is established. The specific research questions of the present study are further justified and defended.

**Chapter 4** introduces Interpretative Phenomenological Analysis and argues that this approach to qualitative enquiry is appropriate for answering the research questions articulated in the present study. The theoretical position of IPA is explored in-depth and the epistemological and ontological basis of enquiry is discussed and clarified. Ethical considerations are also explored with particular reference to interpreting individual subjective experiences.

**Chapter 5** is the methods chapter. It details and justifies the methods employed in this study in order to answer the research questions. As data analysis is included in this chapter, an overview of the superordinate themes is provided in order to present and discuss each one separately in the subsequent findings chapters. **Chapter 6** focusses on the embodied experience of progressive cerebellar ataxia. **Chapter 7** explores participants' perceptions of living with disrupted embodiment in public. **Chapter 8**

portrays participant's accounts of their experiences of healthcare and in particular biomedicine. **Chapter 9** explores how participants found ways to wrest some sense of control over their lives in the face of chronic uncertainty. **Chapter 10** looks at participants' perceptions of physiotherapy and exercise, and the contrast in meaning between self-selected activities and physiotherapy prescribed exercise.

**Chapter 11** further discusses, synthesises and critically evaluates the overall findings of this study, and identifies their unique contribution to knowledge in this discipline. A final reflexive overview is also provided. **Chapter 12** concludes the thesis and presents the implications of this study for academic consideration, further research and practice.

## **Chapter 2**

### **Understanding the Subjective Experience of Long Term Illness: Building a Case for Exploring Progressive Cerebellar Ataxia**

#### **2.1 Introduction**

The purpose of this chapter is firstly to acknowledge the intellectual history of work concerned with understanding the subjective experience of long term illness, and to map the main conceptual ideas. Secondly, this chapter aims to identify the principal contributions and debates from which to initially develop, and later assess, the adequacy and contribution of further empirical work in this field. Specifically, this chapter critically reviews chronic illness scholarship. It also continues to make a case for undertaking a phenomenological investigation of the lived experience of progressive cerebellar ataxia, and for understanding the subjective experience of physiotherapy as one of the few rehabilitation options offered to people living with this condition. Whilst aiming to offer a critical review of the chronic illness literature, it is not the intention of this chapter to anticipate the potential themes of the present study.

This chapter offers a selective narrative review of the literature. Relevant material was appraised and summarised, not with the intention of commenting on methodological quality, but to identify and map the findings, theories and ideas that were considered germane to the contexts of the present study. A traditional narrative review was undertaken because this approach is considered valuable when the intention is to integrate and summarise a range of literature, rather than offering new perspectives or challenging existing theory, as might be expected from a systematic review (Baumeister and Leary, 1997; Pope et al. 2007).

The researcher's professional background as a physiotherapist and lecturer in physiotherapy inevitably involved exposure to, and knowledge of, chronic illness literature. Therefore, it was impossible to approach the literature search without some foreknowledge of key texts and papers (Haverkamp and Young, 2007). Following the 'berrypicking model' outlined by Bates (1989:2), and supported more recently by Barroso et al. (2003) and Walsh and Downe (2005), the literature search began with just a few key texts familiar to the researcher (e.g. Bury, 1991, Charmaz, 1991 and Thomas, 2007) and developed from these texts to include a variety of sources as various leads were followed up, and as thinking shifted and progressed. Adopting a "berrypicking" approach meant that each new piece of information altered the trajectory of the search and, importantly, the conception of the original query, taking the search in new and

unexpected directions. Bates (1989:4) termed this process an 'evolving search' and likened it to picking blueberries in the forest; a 'bit-at-a-time' retrieval process.

Search strategies included; reviewing work by frequently cited authors (e.g. Mike Bury, Sally French, Michael Oliver, Vic Finkelstein and Gareth Williams), following up reference lists; checking citation records; specific database searching, and area scanning (checking neighbouring work on a particular subject e.g. on a library shelf or in electronic records). These methods are recognised by others (e.g. Barroso et al. 2003; Greenhalgh and Peacock, 2005; Walsh and Downe, 2005) as appropriate for identifying and locating relevant material for literature reviews. As the literature searching process was not prospective or linear, the search strategy remained fluid throughout. However, reference was made to the following databases as required; Academic Search Complete, CINAHL Plus, Google Scholar, PsycINFO, Scopus and Web of Knowledge. Search terms included: "lived experience", "subjective experience"; "chronic illness", "long-term illness"; "physiotherapy", "physical therapy", "rehabilitation"; and "impairment", "disability". Records were prioritised if they offered important insights into the lived experience of chronic illness, or the role of physiotherapy, and/or if they helped to place the proposed study in context by establishing what was known in the field and by identifying gaps, areas of debate or controversy.

The goal of the process described above was for the researcher to become familiar with the scope of work and body of knowledge related to the subjective experience of chronic illness in a general sense, without becoming tied to particular theories or models. As discussed by Haverkamp and Young (2007), qualitative researchers often set aside related work in the field to avoid becoming overly familiar and therefore influenced by previously established theories and ideas. This is also an important issue in phenomenologically informed research (Finlay, 2011), and is further discussed in the following chapter. The literature considered in this chapter was gathered and appraised over the course of the study, as part of an on-going process consistent with the approach described by Levy and Ellis (2006). Ideas and theories, as they emerged from the literature, inevitably influenced the researcher. However, by adopting the hermeneutic reflexive approach discussed in chapter one, the researcher endeavoured to maintain a sensitive vigilance, and resistance where necessary, towards the ways in which previous work may influence the direction, development and findings of the present study.

As the aim of this study is to explore and understand the lived experience of progressive cerebellar ataxia, the chapter begins by critically reviewing research focused on the personal and micro-social perspectives of long term illness. Micro-social refers to individuals and how they make sense of their social world, their ordinary and actual behaviour, or everyday life, for example face to face events and actions, and the contexts in which they take place (Bengston et al. 1997). The purpose of discussing research directed towards understanding the subjective experience of long term illness is to provide a background to the thesis, and to place the present study in context. Following this discussion, the macro-social perspectives of living with long-term illness are considered. Macro-social refers to social structures: cultural or normative rules or practices as they influence experience and behaviour (Bengston et al. 1997). Chronic illness is experienced by people who are situated in a particular context shaped by cultural and social norms and practices which form the background and texture against which their lives are lived and are made meaningful. A body of work encompassed by disability studies has drawn attention to disabling, disempowering and oppressive social practices. By doing so, this work has articulated the ways in which social systems may influence the personal experience of chronic illness. The impact of these macro-social structures will not be explicitly explored in the present study but, from a moral as well as a human science perspective, when undertaking research of this kind it is important to be attuned to the possible ways in which these forces may be perceived to affect the lives of participants. The final section of this chapter considers the contested place of bodily impairment in chronic illness research and critically reviews the role physiotherapists play in supporting people living with long term illness and disability. Phenomenology is put forward as a particularly suitable approach for understanding the embodied experience of chronic illness, whilst at the same time offering a means of attending to the full richness of the lived experience.

In noting that terms such as chronic illness and disability may be understood in several different ways depending on individual perspectives, and may be considered offensive when used in particular contexts, convention, where it exists, and usage within contemporary academic texts guided the ways in which these terms were used. Thomas' (2007:14) definition of 'chronic illness' or 'chronic disease' as 'long term and incurable medical conditions' was followed for the purposes of this chapter.

## **2.2 The Development of Micro-social Perspectives of Chronic Illness**

This section traces the emergence of a body of work which explored the subjective experience of chronic illness with respect to the micro-social contexts of everyday life. Through this research, illness came to be understood from an interpersonal perspective, and the subjective impact of illness on individuals and their close relationships began to be questioned and explored. By focussing on the person, and not the condition, such a move represented a re-imagining of conventional medico-centric ways of understanding illness.

Medico-centric refers to a cure-orientated approach to illness: medical authority, secured through expertise in biomedicine, dominates the general understanding of ill health and dictates how others should behave (Lupton, 1997). In these contexts, personal autonomy is diminished and subjective views, values and experiences of illness are generally considered immaterial (Reynolds, 2004). Talcott Parsons' (1951) influential conceptualisation of the "sick role" perhaps best represented the prominent medico-centric position evident in western society in the 1950s and 1960s. In Parsons' view illness was constituted as a temporary state that exempted individuals from the blame of becoming ill, and responsibility from undertaking their usual social roles. At the same time, individuals were obliged to try to restore health as soon as possible by seeking competent sources of help, and, central to this model, by cooperating with medical experts. Illness, by interfering with functional social roles, was considered a form of social deviance, and the sick role, played out according to Parsonian principles, operated as a socially regulated means of directing this deviance into an acceptable process and outcome (Parsons, 1978; SJ Williams, 2005).

The conventional view of Parsons' (1951) sociological model of illness generated sustained critique over several decades, not least for its paternalistic orientations and for classifying illness as deviance, but also for discounting chronic illness, self-management, the patient's perspective and contextual factors such as class, age, gender and ethnicity (Rier, 2010). As the debates about Parsons' theory continued, a body of influential work unfolded from studies conducted in the mid-1960s and early 1970s by the sociologists Anselm Strauss and Barney Glaser (see for example Glaser and Strauss, 1964a, b; 1965a, b). These studies did much to review the problematic assumptions inherent in the conception of the sick role, and to reverse the lack of interest in the subjective lived experience of illness apparent in Parsons' (1951) original model (particularly chronic illness). By emphasising the micro-social contexts of long

term illness, the pivotal role of healthcare as a feature in the lives of people with chronic illness was de-emphasised (but not abolished).

Breaking with sociology tradition by focussing on subjective accounts and life-stories, Glaser and Strauss (1965a, b) recorded the vacillations of terminal illness experience. This work invalidated traditional Parsonian ideas about passive patients gratefully accepting medical or nursing attention. Instead, patients were seen to actively negotiate their interactions with healthcare staff; 'he coaxes, wheedles, bargains, persuades, hints and uses other forms of negotiation' in order to adjust the timing of routines such as bathing, eating, taking medication and undergoing treatment (Glaser and Strauss 1965b: 94). Furthermore, participants in the same study were observed to encounter and navigate a succession of junctures marked by unpredictable deterioration or improvement in their condition which in turn impacted on their sense of self and their social world. Each stage necessitated a re-evaluation of previously successful ways of living, as well as the acquisition and deployment of new strategies and essential resources. This once again reinforced the un-Parsonian concept of patients as active agents in the midst of their illness, and in the approach of their death.

A few years later, in a highly cited commentary, Strauss (1973) emphasised multiple social pressures such as marital stress, role disruption, adjustment and stigmatisation as related problems of long term illness. For Strauss (1973:33) chronic illness brought with it numerous difficulties that required 'organisation of effort' and 'normalizing' processes across multiple social relationships in order to cope with everyday life. Activities focussed on controlling symptoms, preventing or accommodating social isolation, modifying interaction and adjusting to change. Strauss (1973) therefore further stressed the importance of paying sensitive attention to the micro-social contexts of chronic illness, and he continued to dismantle the long-held and privileged position of a purely biomedical approach towards understanding long term illness.

Following on from this early work (Glaser and Strauss, 1965a, b; Strauss, 1973) and its emphasis on the social processes integral to living with chronic illness, Corbin and Strauss (1985) presented a more contextualised understanding of long term illness which made room for, and acknowledged, the specific impact and demands of being ill whilst also attending to the social and personal (emotional and psychological) processes involved in managing everyday life. Sixty couples (one of each couple living with a chronic condition) were interviewed about managing long term illness, and their day to day lives. The deployment of effort across multiple domains described by these participants led Corbin and Strauss (1985) to understand long term illness as a burden

of unending work and care (illness work, personal work and biographical work) which set the tone for much research about illness experience in the following decade.

The findings from Corbin and Strauss' (1985) study were grounded in the authors' commitment to the concept of illness trajectory. This concept described not only the temporal course of chronic illness but also the continued management (work) of illness, and the impact of such work on individuals and their relationships with others. Illness work involved symptom management and crisis prevention. Personal work included relationship management and raising children. Biographical work involved the continual or occasional reconstruction of a person's life, which in turn impinged upon illness work and personal work. Holding onto a life worth living was seen as an almost constant effort jointly undertaken by the individual themselves and their family members.

Corbin and Strauss (1985) argued that people living with chronic illness followed an uncertain illness trajectory, because everyday life and the type of work needed to manage illness and relationships varied from day to day. Carrying out and sustaining an acceptable life appeared to demand frequent monitoring and vigorous ingenuity. Managing a life with a long term illness was therefore presented as an unpredictable, unstable and effortful business necessarily woven in with, and complicating, day to day activities, aspirations and relationships. This understanding of long term illness went beyond the dominant medical and technical rhetoric of the recent past. It moved the perception of long term illness away from the clinical and the abstract, and towards understanding the impact of illness on the personal and concrete lives of individuals and their micro-social worlds. Nevertheless, the illness as work theory proposed by Corbin and Strauss (1985) was not without its critics. Conrad (1987), for example, highlighted the risk of over-conceptualising illness experience as work, by suggesting that further analysis might show that illness work may hold deeper meaning such as taking control and exerting a sense of order and authority over illness.

In summary, the key message emerging from this body of work is that individuals living with long term illness are not the submissive recipients of medical care suggested by Parsons (1951), but are perhaps better understood as active agents, managing the challenges of illness within the context of an on-going life. These findings may help the researcher anticipate issues which also confront people living with a progressive ataxia. For example, the researcher may need to attend to the ways in which participants talk about how they manage the day to day priorities of life with ataxia and how these priorities and ways of coping may vary over time. It may also be important to explore the ways in which participants talk about the impact of ataxia on relatives, friends and carers

as they contribute to the work and effort involved in forging a meaningful and worthwhile life. Conrad's (1987) arguments also remind the researcher to approach the present study with an informed but open mind; with an attitude that prioritises participants' perspectives over and above theories established in the literature, or through the researcher's own experience.

### **2.2.1 The Dominance of Biography and Narrative**

Corbin and Strauss' (1985) reference to biographical work recalled Bury's (1982) influential conceptualisation of biographical disruption, and the impact of chronic illness on the self and identity. Bury (1982) interviewed 30 people living with rheumatoid arthritis and intentionally focussed on those with an emerging diagnosis. The findings suggested that the onset of arthritis was marked by uncertainty associated with disruptions not only to the body (taken-for-granted assumptions about the body and its behaviour were questioned), but also with respect to routine activity and the structure of everyday life. Plans for the future, social relationships, family life and the usual rules governing reciprocity and support were thought to undergo a forceful re-examination in the face of long term illness.

For Bury (1982:169), the meaning of chronic illness was fashioned and negotiated in the context of an intense crisis or disruption and involved 'a fundamental re-thinking of the person's biography and self-concept'. Deliberations about the past with a focus on causation, as well as future projections and the possible impact and course of the illness, formed the critical substance of this re-examined biography. The extent to which individuals could effectively mobilise cognitive and material resources in response to their altered situation was thought to be constrained by: individual circumstances (personal values, life stage, roles, and interests); economic and social conditions and sociocultural constructs (such as causation and blame, stigma, competence and social worth). The experience of illness therefore hinged on a person's ability to draw on reserves to actively manage disruption, and to cultivate supportive social networks. Importantly, Bury's (1982) thesis seemed to posit biographical disruption as an inevitable consequence of living with a long term condition, a view that dominated studies about the everyday experience of chronic illness for well over the next decade (Faircloth et al. 2004).

In the context of ataxia, Bury's (1982) description of biographical disruption may be particularly relevant for those who have idiopathic ataxia, for which there is no known cause. Unanticipated symptoms tend to emerge later in life and might trigger similar

existential questions about causation and progression described by Bury (1982) above. As discussed later in this chapter, the inevitability of biographical disruption was later questioned in the literature but Bury's (1982) argument, that chronic illness is situated within a social and personal milieu that contextualises an individual's experience of long term illness, remains valid and relevant to the ways in which the subjective experience of ataxia might be understood in the present study.

Kathy Charmaz's early work (1983), drawing on interviews with 57 people experiencing a variety of severe chronic illness, added theoretical weight to Bury's (1982) original work. Charmaz (1983:168) recounted the ways in which individuals described their identity as 'crumbling away' as a result of living a restricted life and through enduring social isolation and critical judgement. Participants' concerns lay in their future imaginings about the person they saw themselves becoming: a burden to others, incapable of fulfilling obligations written into valued relationships; and unable to claim identities based on previous roles, activities or interests. Charmaz (1983) articulated a fundamentally broader conception of illness that went beyond physical discomfort to encompass psychological stress; loss and suffering in everyday life. Lawton (2003) also argued that Charmaz's (1983) study emphasised how facets of illness compounded each other, such as the way in which critical appraisal by others prompted withdrawal from society, which in turn restricted social activity and the opportunity for affirmation of a positive self-image. However, whilst possibly resonating with the experiences of people living with less severe long term conditions, the findings of Charmaz's (1983) early work, with its emphasis on suffering and loss of self, may be particular to participants who were severely debilitated and/or housebound. In terms of the present study, Charmaz's (1983) work may still have resonance because the isolation described by participants seemed to stem from critical social appraisal. As noted in chapter 1, people living with progressive ataxia are often judged to be drunk (Rothwell, 1994). Negative appraisals about disordered movement and speech may similarly affect people living with ataxia which may in turn affect not only their sense of self, but also their participation in activities outside the home.

Taken together, this influential body of work (Glaser and Strauss, 1965a, b; Strauss, 1973; Bury, 1982; Charmaz, 1983; Corbin and Strauss, 1985) liberated the study of chronic illness from the constraints of biomedicine and by doing so perhaps spoke for a population whose experiences had been previously overlooked. Nonetheless, as conceded by Bury (1991), such insights emerged without due regard to the more positive steps taken by individuals to successfully mitigate and cope with living with long

term illness. A body of evidence subsequently emphasised that while people with chronic illness may face common problems, much of the response to illness depended upon the particular circumstances of the individual (Bury et al. 2005) and that for some, chronic illness may not be best regarded as a disruptive event in an otherwise consistent and unproblematic life. The following section draws on illustrative examples from the literature to demonstrate the ways in which Bury's (1982) conception of biographical disruption and Charmaz's (1983) emphasis on loss of self, suffering, and downward illness trajectories have been critically interrogated and enhanced by on-going research in the field.

### **2.2.2 Contextualising Biographical Disruption**

Soon after Bury's (1982) conceptualisation of biographical disruption, G Williams (1984) proposed a theory of narrative reconstruction which in some ways pre-empted Bury's (1991) interest in examining the ways in which impairment and other disruptions may be successfully incorporated into an on-going life. The overall premise of reconstruction, built from interviews with 30 people living with long-standing rheumatoid arthritis, acknowledged biographical disruption as fundamental to the chronic illness experience, but went further by describing the ways in which participants sought to piece together key aspects of their biography in order to make sense of their illness within the context of their past and present lives. G Williams (1984:197) described this process as 'an attempt to reconstitute and repair ruptures between body, self, and world' and argued that it answered a fundamental need to restore meaning to the present by reconstructing the past from the fragmentation produced by chronic illness. The emphasis therefore was on repair or recovery of self rather than disruption and loss of self.

A body of research into the experience of long term conditions (Charmaz, 1991; 1999) as well as neurological conditions such as stroke (Becker, 1997) and spinal cord injury (Carpenter, 1994; Hammell, 2004), supported G Williams' (1984) ideas. Illness narratives, characterized by the influential work of Zola (1982), Kleinman (1988) and Frank (1997), added to the perception that people living with chronic illness made sense of their lives by narrating their life story and, by doing so, reconstructed a new sense of self. These narrative orientations, embedded in much of the work noted above, offered powerful insights into the profound re-thinking undertaken by people living with chronic conditions. Storied accounts worked to integrate the disruption of illness into a coherent whole and to sustain a sense of biographical continuity. For example, Charmaz (1999:372), drawing on interviews with people living with chronic illness, stressed the

way in which narrative reconstruction helped them 'learn new ways of managing life that transcend[ed] immediate suffering'. In this way, re-storied biographies created order from disorder, and achieved some sense of completeness and acceptance of a changed self. These ideas about re-storying a life as an attempt to retain a sense of stability and purpose in the face of long term illness, offered a theoretical basis for conceptualizing chronic illness and studying it from multiple perspectives and contexts (Hydén, 1997; Lawton, 2003). However, the assumptions underlying narrative reconstruction (e.g. that narrative reconstruction was inherently restorative) and the inevitability of biographical disruption were challenged in subsequent critiques and through empirical research. Illustrative examples are discussed below.

Carricaburu and Pierret (1995) interviewed 42 asymptomatic HIV positive men in order to understand the consequences and the meanings ascribed to an HIV positive status on everyday life and personal identity. Half the men had haemophilia and were infected with HIV through blood transfusion. All participants described re-working their sense of identity in the face of HIV infection, but did not describe biographical disruption in the same way as Bury (1982). For example, for those haemophilic men who had previously rejected the prevalent "normalising" discourse associated with haemophilia at the time, and who had already organised their lives around the illness trajectories described above (e.g. by refusing to marry or to have children), HIV infection resulted in biographical reinforcement and a sense of continuity rather than disruption. However, for men who adopted "normalising" strategies to diminish the impact of haemophilia in their everyday lives, HIV infection disrupted their taken-for-granted way of understanding their illness, and provoked a critical reappraisal of their sense of identity. HIV infection for this group of participants resulted in biographical disruption that also entailed biographical reinforcement because, by re-thinking their biography, haemophilia came to be seen as an essential part of their identities. The findings from this study therefore qualified the biographical disruption thesis and signaled the need for a more fine-grained understanding of this concept, and its reappraisal as central to chronic illness experience.

In a much quoted study, Pound et al. (1998) found that elderly stroke survivors living in the East End of London viewed their stroke as another anticipated hardship in their already difficult lives. The stroke was not perceived as a disruptive event because it was part of a long established pattern of living through, and with, adversity. Similarly, Sanders et al. (2002) found that elderly people living with arthritis incorporated the pain and disability associated with this condition into an already imagined old age. The

significance and consequences of arthritis were considered part of “normal” aging. Likewise, Faircloth et al. (2004) interviewed mostly male participants, over the age of 65 with several co-morbidities, about their experience of stroke over a twelve month period. In this particular group, the disruptive consequences of stroke were minimised with respect to what was considered “normal” in the life experience of participants. Stroke was understood as simply another component of a person’s ‘biographical flow’ (Faircloth et al. 2004:256), an anticipated part of life.

Carricaburu and Pierret’s (1995) conception of biographical reinforcement, the notion of biographical flow (Faircloth et al. 2004), as well as the influential studies conducted by Pound et al.(1998) and Sanders et al.(2002), emphasised the adaptive processes undertaken by people living with chronic illness and the ways in which illness, which may be disruptive in and of itself, may not be narrated into a disrupted biography but integrated into a complex, personally meaningful and on-going life-story. Therefore, a critical application of the biographical disruption thesis to chronic illness research further evinced the importance of attending to the particular context of chronic illness experience. Participants in Bury’s (1982) original study considered arthritis as an unexpected and unwanted intrusion into their relatively young lives, and as such described profoundly disrupted life trajectories. In the studies described above (Carricaburu and Pierret, 1995; Pound et al. 1998; Sanders et al. 2002; Faircloth et al. 2004) age, co-morbidities and the type of illness, as well as social circumstances, shaped the chronic illness experience. By doing so, these studies cautioned against an uncritical application of biographical disruption as the primary vehicle through which illness experience should be understood.

Although none of the studies discussed above explored the perceptions of people living with progressive cerebellar ataxia, some of the findings may be relevant to the contexts of the present study. For example, for those who have family members with ataxia, the emergence of symptoms may be confirmatory, and act as part of their anticipated biographical flow, whereas those who developed symptoms as part of idiopathic ataxia may recount a more disrupted life trajectory. Nevertheless, this reviewed work also suggested that these experiences are highly contextualised, and therefore difficult to predict without undertaking the sort of qualitative enquiry proposed for the present study.

### **2.2.3 The Limits of Narrative**

Woods (2011) acknowledged the narrative orientation prevalent in much illness related research as playing a significant and important role in illuminating the distinctive qualities of a person's identity, traditionally excluded from biomedical understandings of health and illness. However, drawing on Strawson's (2004) anti-narrative polemic, Woods (2011) argued against what she saw as the development of a narrative imperative in academic scholarship i.e. that a person's identity and illness experience must be held in linear narrative form, that illness could only be understood within an on-going story of a person's life, and that sense making (about illness experience) could only be generated through narrative. Woods (2011:76) called for scholars to 'denaturalise' narrative by exploring other ways of understanding illness experience, and to resist the taken-for-granted assumption that individuals are naturally able and predisposed to adopting a narrative mode of communication, and of typically seeing their lives as some sort of unfolding story. Phenomenology, photo-elicitation and metaphor were identified as appropriate alternatives for embracing diverse perspectives and means of self-expression, and for gaining access to lived experiences that may be tentative, incomplete, fragmentary and unstoried. Carel (2011) and Sartwell (2006) argued similarly in calling for situating narrative in amongst other, equally valued, modes of communicating and understanding subjective experience. Illustrative examples from the literature which support this view are discussed below.

In this first example, Reeve et al. (2010) intentionally set out to explore whether self-identity was dependent upon the maintenance of a continuous personal narrative - a core assumption underlying the biographical model of chronic illness. Reeve et al.(2010) critiqued this assumption, and its emphasis on a reflexive-cognitive self, for failing to account for embodied and emotional experiences, and as such for providing an inadequate reflection of individual lived experience. In this study 19 people with terminal cancer who were considered at risk of distress were asked to tell the story of their illness in the context of their own lives. Reeve et al.(2010) intentionally looked for examples of disruption. Unsurprisingly the participants' accounts took on narrative form and reflected the description of biographical flow put forward by Faircloth et al.(2004), as well as an opposing concept termed 'narrative fracture' (Reeve et al. 2010:183). Flow referred to participants' orientations towards maintaining continuity of everyday life, rather than efforts to maintain a continuous meaningful biography. Illness made this aim difficult to achieve, but embodied and emotional work, rather than cognitive reflexive effort, sustained narrative flow. Everyday life involved an iterative cycle of expending and replenishing physical and emotional energy. Participants focussed on meaningful

activities such as “getting on” with doing the housework for example, and recouped emotional and physical resources by spending a day in bed or allowing themselves time and space to grieve about the difficulties they faced. Physical and emotional exhaustion (rather than disruptive events) heralded the onset of biographical fracture, whereby everyday activities became unsustainable.

Reflecting on these findings, and whilst admitting the intellectual currency of biographical theory, Reeve et al. (2010) argued that a strict application of the biographical narrative/cognitive view of individual illness experience overstated the extent to which participants’ accounts were consistent with a model of a reflexive self looking for meaning. The authors further argued that the biographical model underplayed the contribution of emotional and embodied ways of living with a terminal illness which were firmly situated in the here and now of everyday experience. Doing or being in a way that was emotionally energising, or which boosted creative responses to adversity, was thought to bolster self-agency and resilience, as well as offset the negatively charged experiences of living with long term illness (such as isolation, depression, loss of identity and role, stigmatization and disruption). However, living with a terminal illness, being psychologically close to death, may have limited the extent to which participants projected beyond their everyday activities and preoccupations. Reeve et al.(2010) suggested that although participants encountered threats to narrative self-identity, these were usually bracketed off, or put to one side. Therefore these findings may be particular to this group of terminally ill participants. However, as discussed below, further studies with people living with long term illness, but not terminal illness, lend support to the view proposed by Reeve et al.(2010) that engagement in personally meaningful activities or ways of being may protect against the illness stressors, biographical crises and other depleting consequences of chronic illness identified in previous studies (e.g. Glaser and Strauss, 1965a, b; Strauss, 1973; Bury, 1982; Charmaz, 1983; Corbin and Strauss, 1985).

Without diminishing the significance of the deleterious effects of living with chronic illness, a body of work has further identified that engaging in physical, social or creative activity may have profoundly positive effects on subjective well-being. To illustrate, Reynolds and colleagues (Reynolds, 2003; Reynolds and Prior, 2006; Reynolds and Lim, 2007; Reynolds and Vivat, 2010 and Reynolds and Prior, 2011) used phenomenologically informed methods to deepen the understanding of the beneficial role of creative activity. Individuals living with a range of long term conditions (e.g. multiple sclerosis, chronic fatigue syndrome, cancer and arthritis) talked about the

restorative capacity of art-making, which worked to maintain a familiar sense of self and social identity that was not defined by illness. Furthermore, creative occupations confirmed on-going capability, increased satisfaction with daily life and also helped to resist the harmful and well recognised physical, existential and social corollaries of chronic illness. Likewise, physical activity, for example sea kayaking (Taylor and McGruder, 1996) and scuba diving (Carin-Levy and Jones, 2007), were valued by people living with spinal cord injury for providing novelty and stimulation, but also for affording enriched social experiences and for promoting a sense of social competence and equality. Similarly, volunteering (Barlow et al. 2005) and engaging in reciprocal relationships (Hammell, 2007) fostered opportunities whereby individuals living with chronic conditions contributed to the lives of others, which in turn also promoted a sense of competence, belonging and self-worth. This sort of work has done much to re-balance the negative preoccupations of the early sociology studies, and the reliance on a strictly applied biographical or narrative approach to understanding long term illness. Furthermore, the application of phenomenological and other qualitative methods opened out the understanding of the experience of chronic illness by acknowledging the value of emotional and embodied perspectives.

Critical insights from the work discussed above demonstrated that not all people living with a long term condition such as progressive ataxia will recognise that they have a story to tell, or will be able to narrate their life experiences in a cognitive-reflexive mode (a way of talking or telling subject to normative constraints). Furthermore, Reeve et al.(2010) demonstrated that holding onto a valued or preferred self-identity did not necessarily hinge on maintaining a discursive self, but in doing and being in ways that followed the patterns of everyday life (energising activity punctuated by periods of recovery and reflection). Further examples from the literature (e.g. Reynolds and Prior, 2006) also demonstrated that an appropriately sensitive enquiry would enable participants to talk about the things that matter to them, and the enjoyable aspects of their lives, without necessarily focussing on “coping” with long term illness (as a cognitive reflexive construct) or dwelling disproportionately upon the hardship and difficulties of life with chronic illness. These perspectives and arguments were used to inform the development and shape of the interviews undertaken within the present study, as discussed in more depth in chapter four (Methodology).

Thus far, this chapter has focussed on research that would fall into Thomas’ (2007) categorisation of micro-social experiential studies of chronic illness and disability. Such research is typically concerned with individuals and their personal world, an

interactionist perspective that, whilst taking subjective experiences seriously, pays less attention to the broader political and macro-social forces that impact on the experience of long term illness and disability. By contrast, researchers working in the field of disability studies have explored the lived experience of illness and disability in order to intentionally expose the ways in which social structures and unexamined cultural practices (e.g. medical authority derived from Parsonian principles) disable and oppress people living with chronic conditions. Without anticipating the findings of the present study, the next section of this chapter provides a selective summary of relevant research and critique from this substantial body of scholarship, and considers the main arguments in the context of the development of the present study.

### **2.3 Macro-social Perspectives and Disability Studies**

Campaigners, commentators and researchers whose work falls into the category of disability studies have illuminated and emphasised the impact of disablism in the lives of people living with long term illness (Thomas, 2007). The social oppression paradigm, first articulated in the 1960s (Hunt, 1966), evolved from an emancipatory movement, advanced by disability activists committed to promoting the civil rights and social interests of disabled people (Thomas, 2007). This movement hinged on the understanding that impairment was not the cause of disability. Instead it was proposed that disability was engendered by social oppression, such as the exclusion of people with impairments from employment, education and main stream society. This thesis was put forward in a ground-breaking manuscript, authored by Vic Finkelstein and Paul Hunt, published under the auspices of The Union of the Physically Impaired Against Segregation (1976) and entitled 'The Fundamental Principles of Disability'. It laid the foundations for the development of the social model of disability (Oliver, 1983), considered below. Exclusionary mechanisms (social marginalisation and spatial segregation) were traced back to the socio-economic developments of the industrial revolution (Finkelstein, 1980; Oliver, 1990). In this era, people with impairments were commonly separated from those able to contribute to an economic system founded upon a physically capable workforce. Deemed incapable of working, impaired individuals were often subject to enforced dependency and state control (inadequate state welfare, institutionalisation, treatment regimens and medical supervision), a situation that persisted throughout most of the twentieth century (Abberley, 2002). Disablist practices, and culturally entrenched narratives emphasising social deviancy, were thought to further disempower people with impairment and, via internalised oppression (Swain and French, 2008; Oliver, 2009), contributed to the articulation of a negative sense of self

(Thomas, 2007). The social oppression paradigm also served to remind researchers of the ethical dimensions embedded in the process of undertaking research about living with chronic illness, such as the risk of doing research “on” disabled people and the long history of conducting research that was not grounded in, or relevant to, personal experience (Oliver, 2009).

Working within the social oppression paradigm, Oliver (1983) developed the social model of disability as an alternative to the previously dominant individual (medical) model and its focus on personal tragedy. Oliver’s (1983) description and later elaboration of the social model further endorsed the view that disability was not caused by impairment but by social restrictions, or environmental, structural or attitudinal barriers (Oliver, 1996), imposed on people with impairment. The social barriers concept was subsequently supported by multiple studies conducted across multiple social contexts (Thomas, 2007; French and Swain, 2008).

The importance and significance of the social model of disability was founded upon its ability to function as an organisational focus for collective action and, with respect to the medical model, for ‘providing an alternative understanding of the experience and reality of disability’ (Swain et al. 2003:24). Oliver (2009) explained that the body was intentionally left out of the social model because diverse impairments were deemed incapable of generating political capital; activists wanted the focus of the movement to be on the shared causes of disability and to distance themselves as far as possible from the impairment-led individual (medical) model of disability. The body was arguably further pushed to the margins by male dominated theorists and activists who relegated impairments and suffering to the realm of the personal and private; a topic not fit for public discourse (Thomas, 2007). However, this decision led to criticisms that research about chronic illness and disability was ‘strangely disembodied’ (Thomas, 2007:138).

Despite the substantial gains made by the social model when used as a tool for promoting social and political change for disabled people (Oliver, 2009), many researchers and commentators (e.g. Swain et al. 2003; Hammell, 2006; French and Swain 2008, 2004; Oliver, 2009) argued that the individual (medical) model of disability remained dominant and uncontested in health and social care and within contemporary rehabilitation practice. The dominance of the medical model of disability provoked researchers to explore the ways in which the power and influence exerted by health and social care professionals (doctors, physiotherapists, occupational therapists, social workers) served to sustain cultural discourses and social stereotypes that framed people with impairment as at once, and always, dependent victims in need of care (Thomas,

2007). As a result of these endeavours, a considerable body of qualitative research (some of which was discussed previously e.g. Taylor and McGruder, 1996; Carin-Levy and Jones, 2007; Reynolds and Prior, 2006, 2011) enhanced by researchers and writers in the field of disability studies (e.g. Morris, 1992; McBryde Johnson, 2003; French and Swain 2004; Oliver, 2009), demonstrated, contrary to the medical model, that for disabled people, the necessary requisites for living a life that has meaning and which generates a sense of self-worth, included ways of being that give purpose to life, a sense of belonging and contributing, and opportunities for exerting choice and control. By taking the body, at least in part, out of the picture, this research endorsed the validity of the social model of disability and demonstrated that quality of life was not dependent upon the presence or absence of impairments, but instead subjective and social factors.

With reference to the present study, the corpus of work outlined above would suggest that qualitative enquiry has to be sensitive to the socio-historical as well as the personal and micro-social contexts of individual participants, for example personal experiences of stigma, marginalisation and exclusion. Macro-social perspectives of disability also seem to problematize physiotherapy and to suggest that physiotherapists' traditional interest in repairing impairment and "normalising" the body (Nicholls and Gibson, 2010) may be built on a mistaken premise. As G Williams (1996:200) observed: 'if the problem is not the need of the individual to adapt to the impairment, but rather the complex process of negotiating the interactions out of which daily life is created, then the role of professional experts as people who do things to the impaired body is clearly limited.' What physiotherapists "do to the ataxic body" is not well understood or based on a significant body of evidence, and yet physiotherapy is recommended for people living with progressive ataxia (Ataxia UK, 2009). By exploring how people living with progressive ataxia experience physiotherapy, the present study might shed light on what, if any, aspects of physiotherapy are valued by participants. It may also contribute to the ongoing debate about the place of physiotherapy in the lives of people living with long term illness, and, as discussed in more depth below, the extent to which contemporary physiotherapy practice may be underpinned by biomedical orientations that perhaps do little to address the social dimensions of disability.

In summary, research and commentary from within the social oppression paradigm emphasised the macro-social contexts that worked to marginalise, exclude and disable people with chronic illness. The body was problematized and the role that impairments played in shaping the lives of people living with chronic illness was reconsidered. The work reviewed in this section places the present study within an historical, political,

social and, perhaps more importantly, a moral context. It proscribes research that treats participants as tragic victims, or as abstract, decontextualized objects of enquiry. Instead, the work reviewed above arguably champions the sort of qualitative enquiry encouraged by Packer (2011:384) with its focus on 'concrete people, in specific material circumstances'. In undertaking this type of qualitative enquiry, researchers would attend to the activities, relationships, aspirations and social structures that give purpose to a life lived with chronic illness, as well as the challenges and difficulties that may be faced. The extent to which it is possible to privilege the views and experiences of participants, to be sensitive to the situations and socio-cultural conditions that constitute individual lives, and the reflexive work required in order to do so, is a matter of debate and is discussed in detail in chapter 4 (Methodology). The next section argues that phenomenological enquiry offers a means by which these complex territories could continue to be sensitively negotiated in future research and in particular within the present study.

#### **2.4 Contextualising Impairment: Phenomenological Approaches to Understanding Lived Experience**

Traditionally, physiotherapists and other rehabilitation professionals, however well motivated towards "doing good", were thought to subscribe to the assumption that people with impairments would wish to be treated and cured, or at least to optimise their physical function (Hammell, 2006; Thomas, 2007; Andreou, 2010; Nicholls and Gibson, 2010). By endorsing the medical model in this way, rehabilitation professionals gave themselves a mandate to exercise power and authority in people's lives under the auspices of treatment and care (Thomas, 2007). The situation for physiotherapists would seem to be particularly problematic in this regard. Nicholls and Gibson (2010:497) cogently argued that physiotherapists acquire their professional identity, status and financial security 'because of their expertise in managing health problems that have at their core the function and dysfunction of the body.' Furthermore, physiotherapists' long standing affinity with biomedicine, their profoundly mechanistic understanding of the body, and their status as movement scientists, has meant that the body as a philosophically complex construct has been 'almost entirely bypassed' by the profession (Nicholls and Gibson, 2010:497). If the argument stands that impairments are not personally disadvantageous, and if quality of life only rests on subjective experience, then it would seem that the position of rehabilitation professionals in general and the role they play in the lives of people with chronic illness is at risk (G Williams, 1996; Hammell, 2006).

In taking the debate forward, Nicholls and Gibson (2010) suggested that in order to sustain the value and purpose of the profession, and to more effectively respond to the subjective experiences and multiple dimensions of health and illness (including political and social dimensions), physiotherapists should reassess their long held view of the primacy of the biological body and instead take on an embodied perspective. According to Marcum (2004:312), a phenomenological model of the embodied person 'reclaims the person's wholeness or integrity especially with reference to the lived context'. An embodied understanding of health and illness, and progressive cerebellar ataxia in particular, would therefore make room for the social and political dimensions of disability and long term illness, whilst also integrating relational perspectives occurring on a micro-social level, as well as felt bodily experiences such as pain, suffering and impairment.

Others in the disability movement and in disability studies have spoken similarly. Several disability theorists, including feminist voices, argued for retaining an understanding of the body that incorporated the physical or impaired body into an integrated model of illness and disability (Morris, 1992; Crow, 1996; Hughes and Patterson, 1997; de Wolfe, 2002 and Thomas, 2007). For example, Crow (1996:58) explained that 'impairment is not always irrelevant, neutral or positive ... when pain, fatigue, depression and chronic illness are constant facts of life'. De Wolfe (2002:255) similarly argued for 'a more inclusive and diverse movement, which can encompass those whose suffering is resistant to social accommodation.' Thomas (2007) and others (e.g. Kelly and Field, 1996) have also called for researchers interested in chronic illness experience to reintegrate the body into their exploration of the personal, cultural and social contexts of illness and disability.

With respect to the arguments outlined above, impairments are perhaps more properly understood as 'complex bio-social phenomena', engendered and given meaning within a multifaceted social and cultural structure (Thomas, 2007:137). This way of understanding the impaired body has much in common with phenomenological perspectives which offer an account of the body that admits its experiential as well as its social and political significance (G Williams, 1996; Smith et al. 2009; Finlay, 2011). These ideas suggest that leaving the body out of research about long term illness or disability would risk failing to recognise the ways in which impairment shapes the lives of disabled people, and would seem to inevitably lead to an unnecessarily blurred view of a phenomenon ostensibly fundamental to understanding the human condition.

Exemplars that take a phenomenological view of the body, and therefore explore illness experience in ways recognisable and consistent with the views of disability theorists, can be found in research using interpretative phenomenological analysis (IPA) and aligned approaches in the human sciences. For example Smith et al.(2009) used IPA to explore one woman's experience of the personal meaning and impact of haemodialysis, a life-saving biomedical intervention for people living with end-stage renal disease. For the participant in this study haemodialysis came to mean passivity, loss of control, bodily invasion, fear and institutionalisation which ultimately undermined her sense of identity. By taking a phenomenological approach, the authors were able to show how these findings could be used to alert healthcare practitioners to the ways in which biomedical interventions may be interpreted by individuals. It was theorised that haemodialysis, as an intervention that necessitates regular and frequent hospital visits and bodily penetration to access and clean the blood, may be particularly open to being constituted as assaulting and eroding the sense of self. This work was also able to show how an individual's perception of this sort of intervention could be altered by enhancing the patient's sense of control, by involving them in the planning and organisation of their care. These ways of humanising medical interventions by questioning cultural norms ingrained in healthcare practice could be seen as attending to some, if not all, of the issues raised by disability theorists.

As chapter one outlined, and as the following chapter underlines, the personal meaning and significance of ataxia as an embodied phenomenon has not been explored in the literature. Doctors and rehabilitation professionals examine people living with ataxia and, from this outsider's view, describe and classify the impairments they observe in objective terms. Responses to these biomedically constructed problems are also commonly delivered by people who have no experience of impairment themselves, and with little guidance on which to base their interventions. What seems to be lacking in the approach taken by rehabilitation professionals towards ataxia is, as articulated by Crow (1996) in relation to impairment in general, firstly, an understanding that people living with ataxia will apply their own meanings to their personal experiences of impairment, secondly, that these understandings may alter over time and through changes in circumstance and social mores, and thirdly, that understanding how people talk about their embodied experiences of ataxia constitutes knowledge that may be used to question existing practice and to develop more informed and responsive healthcare. The present study, in keeping with the disability theory perspectives described above, sought to explore the personal lived experience of progressive ataxia, and to understand the significance of the body and the experience of ataxia from a bio-social perspective.

## 2.5 Summary

This chapter explored and critiqued a body of evidence which has contributed to the understanding of chronic illness, disability and healthcare from multiple perspectives. The evolving, arguably key work in this field was chronologically tracked, starting with work emerging from the 1950s. In direct opposition to Parsonian conceptions of the sick role (Parsons, 1951), this seam of research concerned itself with understanding personal suffering, and the impact of illness and disability on the micro-social worlds of individuals and the important people in their lives. Negative experiences and ways of living with chronic conditions were commonly described and discussed. A propensity towards narrative approaches was identified in these studies, and whilst recognising its strengths, this methodology was also critiqued for representing narrative as a universally accepted means of articulating and re-framing illness experiences. Phenomenological methods were identified as possible alternatives for understanding experiences that may be partial, incomplete and unstoried. More recent experiential and phenomenologically informed work identified common experiences that contributed to making life meaningful, rich and fulfilling in the face of illness and disability. Scholarship within the discipline of disability studies illuminated alternative macro-social perspectives, and the development of politically and emancipatory oriented research. This work identified the many ways in which disabled people were excluded from full participation in everyday life through the restrictions imposed by disablist attitudes, cultures and environments. Impairment as a contested concept in health and illness research was appraised in light of the arguments presented from the perspective of the social oppression paradigm, and through the lens of physiotherapy practice. It was acknowledged that the body was perhaps under-theorised in physiotherapy, and furthermore that the profession's insistence upon viewing illness and disability through a biomedical lens limited the extent to which alternative perspectives of illness and disability informed practice. Phenomenologically informed research which takes an embodied view of impairment, illness and disability was identified as a valid means of exploring the lived experienced of people living with long term conditions.

In conclusion, it would seem that although much research has been conducted in the respective fields of chronic illness and disability, and common themes have emerged about the experience of living with long term conditions, the lives and voices of people living with progressive cerebellar ataxia have been absent from this work. Furthermore, the research considered in this chapter favoured, on the whole, either macro (political/sociological) or micro (personal) conceptions of human experience. This sort of dichotomising of human life, whilst in the past useful and instructive, struggles to survive

careful scrutiny. This is because, as this chapter has argued, understanding chronic illness requires not only an exploration of the individual, rooted as they are in their cognitive, psychological and existential world, but also, simultaneously, a commitment to perceiving the underlying social structures that may shape a person's experience. Phenomenologically informed research, with its understanding that the person and the world is intertwined (Finlay, 2011) has much to offer in this respect. This chapter has therefore started to make a case for adopting phenomenology as an appropriate means of sensitively exploring the lived experience of progressive cerebellar ataxia, and for developing a contextualised understanding of impairment and embodiment in the everyday lives of people living with this condition. Given the researcher's professional affiliations, and interest in understanding how patients experience physiotherapy, phenomenology would also seem an appropriate means by which these experiences could also be explored in the present study.

## **Chapter 3**

### **Literature Review**

#### **3.1 Introduction**

An initial literature search was undertaken in 2006 (at the start of the project). The following electronic databases were examined; CINAHL Plus, AMED and PsycINFO using key search terms; 'ataxia' AND 'experience' OR 'qualitative' OR 'perspective' OR 'physiotherapy' OR 'physical therapy'. Using this search strategy no experiential accounts or qualitative research about living with ataxia or the experience of physiotherapy for people with ataxia were uncovered. As the literature search was based on an examination of comprehensive, authoritative and internationally recognised sources of published research in diverse fields including; biomedicine, health sciences, psychology, physiotherapy and rehabilitation, it suggested that the experience of living with a progressive ataxia had not, at that time, been explored or understood from the perspective of people living with this condition.

A further review of the grey literature (The Ataxian, the Ataxia UK quarterly magazine for members and the Ataxia UK website) identified one paper (Box et al. 2005) which briefly described the experience of two parents caring for children living with Friedreich's ataxia (FRA) and included one short narrative about living with an unidentified cerebellar ataxia (discussed in the review below). At the same time as the initial literature search was being undertaken, requests from Ataxia UK for first person accounts of living with late onset ataxia (Ataxian, 2006) produced a groundswell of interest (Ataxian, 2007) culminating in the publication of one short narrative account, one leaflet containing short stories about life with ataxia and an information and advice fact sheet for people living with this condition (Ataxia UK, 2007a, b, c). Formal discussions with the research committee of Ataxia UK further supported the view that there was a latent and urgent need to undertake qualitative research which focussed on exploring the lived experience of cerebellar ataxia and participants' perspective of physiotherapy. These discussions and the submission of a formal grant application ultimately led to the successful partial funding of the present study. The rationale for the study was therefore founded upon the need to listen to, heighten awareness of and better understand the personal experience of living with a progressive ataxia; critical perspectives that seemed to have been overlooked in the academic literature.

Whilst the initial literature search and subsequent discussions with Ataxia UK (in 2006) established a rationale for the present study, the study itself developed over the

following five years during which time research in the field of interest expanded and progressed in several directions. Most of the literature relevant to the present study post-dates the data collection period which occurred during 2007. During the course of the study (2006-2012) database searching was repeated at intervals; a final in-depth literature search and analysis was conducted in November 2011 (following completion of the data analysis) which was again updated in August 2012. This iterative process was in keeping with that described by Levy and Ellis (2006) who regarded the literature review as an evolving and dynamic endeavour which only ends at the completion of the study itself.

The purpose of the following in-depth review of the literature is to provide an up to date critical analysis of work that has been conducted in the field and which has some bearing on the present study. The reasons for doing this are twofold. Firstly, the present study did not take place in a vacuum. It is important to convey the extent and significance of the contemporaneous work to the reader so that the present study can be fully situated within the larger body of relevant and, at least in part, simultaneously conducted research. Freezing the literature review in 2007 would create an artificial environment in which to place this study and would risk distorting both its relevance and its contribution. Secondly, this new work that has evolved alongside the present study cannot be unread; it will have informed and contextualised the thinking and perspectives of the researcher and therefore should be discussed and evaluated in its entirety.

The in-depth literature review focussed on exploring and understanding the available research concerning the lived experience of progressive ataxia. This type of review is most closely aligned to the purposes of a critical narrative review rather than a systematic review which is usually considered more appropriate for drawing conclusions about the effectiveness and efficacy of interventions (Pope et al. 2007; Baumeister and Leary, 1997). As noted in the previous chapter, traditional narrative reviews aim to summarise, compare and interpret the literature but usually pay little attention to methodological quality or to systematically or exhaustively searching for relevant evidence (Pope et al. 2007). Critical narrative or second generation reviews, by comparison, report search and selection processes, draw together existing knowledge of a specified topic and develop research questions by attending to weaknesses, problems, inconsistencies and ambiguities in the oeuvre (Pope et al. 2007; Baumeister and Leary, 1997). Narrative reviews are also well placed to consider methodological diversity, an important issue for IPA research where qualitative as well as quantitative work in the field of interest often has to be considered (Smith et al. 2009). The critical

narrative review that follows was undertaken with the intention of placing the present study in context as well as highlighting the strengths and limitations of previous and concurrent work.

### **3.2 Searching the Literature**

A literature search, whose focus lies in identifying work where the borders are not well defined and that may cross disciplinary and methodological boundaries, can be a complex, time-consuming and resource depleting enterprise (Dixon-Woods et al. 2006; Shaw et al. 2004). One of the reasons behind the difficulties in conducting a comprehensive qualitative literature search is that the electronic indexing system for qualitative research lacks precision: several complex search strategies might be required to locate potentially relevant records but within the total sample of identified papers there may be very high redundancy (Shaw et al. 2004; Gorecki et al. 2010). Whilst the effectiveness and efficiency of search strategies to identify qualitative studies still needs to be improved (Noyes et al. 2011) considerable progress has been made in the last ten years. Medline introduced the MeSH (Medical Subject Headings) term 'qualitative research' in 2003, complementing CINAHL Plus' introduction of 'qualitative studies' in 1998. Furthermore, several index systems and methodological filters have been designed (e.g. at the Centre for Reviews and Dissemination) and optimal search strategies for finding qualitative research have been identified and tested in the larger databases (Wong et al. 2004; McKibbon et al. 2006; Walters et al. 2006 and Wilczynski et al. 2007). This latter body of work undertaken by the Hedges Team at McMaster University demonstrated that it was possible to reduce search complexity by using optimal search strategies whilst retaining comprehensiveness, thus ensuring that very few articles were missed. The standard qualitative search strategy available in CINAHL was thought to offer the most efficient and effective means of identifying the majority of relevant papers (Flemming and Briggs, 2007). However, as none of the main databases were infallible in the studies noted above, it remains necessary, for methods-based searches, to use multiple databases which should include, as a minimum; EMBASE, MEDLINE, CINAHL and PsycINFO (McKibbon et al. 2006).

As the focus of the literature search was directed towards finding qualitative research relevant to the lived experience of cerebellar ataxia, the highly sensitive but less complex search strategies advocated by Wong et al. (2004), McKibbon et al. (2006), Walters et al. (2006) and Wilczynski et al. (2007) were used as a guide to formulate a methods-specific search strategy for each of the main bibliographic databases. A

framework was developed to maximise sensitivity (comprehensiveness) over and above precision (relevance of identified papers) in the first instance. In addition to these searches, a brief examination of published qualitative systematic reviews suggested that the following databases should also be searched; Academic Search Complete, AMED, the Cochrane Library, Web of Science, ZETOC and SIGLE (System for Information on Grey Literature in Europe, 1980-2005). Following Finlay (2011), dissertations and theses as well as professional and special interest websites and key journals were also searched.

It was anticipated that, in addition to searching for qualitative studies, mixed method studies may also contain relevant information for the present study. Gorecki et al. (2010) found that locating qualitative work in mixed methods studies was problematic therefore, where feasible, a separate search was conducted using free text or subject headings or MeSH specified terms for mixed methods research as proposed by the University of Washington (2011).

Finally, Greenhalgh and Peacock (2005) argued that in situations where the literature may be hard to find, additional strategies and informal searches should be used to complement traditional methods because database-restricted searches risked omitting up to 70% of relevant research. Additional approaches for the present study were also informed by the recommendations of Barroso et al. (2003) and Walsh and Downe (2005) and included; personal contacts and academic networks, existing knowledge, personal resources, serendipitous findings (often whilst looking for something else), and the development of new avenues for searching whilst the search unfolded, for example through author, citation and reference tracking.

In summary, a methods-based literature search which focussed on the exploration and understanding of lived experience in firstly qualitative research and secondly mixed methods research, was combined with the subject-specific search term 'ataxia'. The single operator 'ataxia' was considered sufficient as a search term following an exploratory search that included combinations of words (e.g. cerebellar ataxia) which were found to be redundant. Boolean operators (AND / OR / NOT) and abbreviations for plurals were used where necessary. Searches were restricted to work published in English, with databases searched from inception to November 2011 (updated to August 2012), the search field for key words was limited to the abstract, and additional strategies as outlined above were used to augment the search. An overview of the search strategy is presented in Appendix A1.

### 3.3 Literature Search Results

A total of 3405 papers were identified using the search strategy described above. Nineteen papers were selected following abstract review and where necessary by reading the full text (Appendix A2). Papers were rejected for many reasons but principally because the search was comprehensive rather than precise. For example, many papers including “experience” in the title or abstract referred to the experience of using specific interventions or tests, or described particular cerebellar ataxias but not subjective experiences. Seven papers were identified from database searches, five through citation tracking, two whilst looking for something else, two through publication searches, and three were found via the grey literature (Appendix B). Studies were included if they were concerned with understanding the lived experience of ataxia (using any qualitative approach) or through using mixed methods whereby personal perspectives, priorities and concerns might be illuminated. Of the 19 selected papers 68% (n = 13) were published in the last five years (2007-2011) i.e. during the development of the present study. The rest (n = 6) were published over a 20 year period from 1987 to 2005. As with the preliminary literature search, none of the identified literature explored the experience of physiotherapy for people living with ataxia.

### 3.4 Critical Review of the Literature

Opinion is divided on the value of formal assessment tools for critiquing qualitative research. This debate is concerned with the nature of knowledge and whether qualitative research intends to meet and therefore can be judged by the same criteria as that of quantitative research (Mays and Pope, 2006). Critically it seems that what might be considered as some of the most important qualities for assessment are also those that are the most difficult to judge (Dixon-Woods et al. 2004). Kuper et al. (2008:687) have argued, for example, that the thorough assessment of qualitative research is ‘an interpretative act’ that ‘requires informed reflective thought’ rather than the application of a simple scoring system. Therefore effective critical review of qualitative studies is perhaps less about the rigid application of a set of rules and more about using critical appraisal tools to guide the process of interpretation and exploration. The Critical Appraisal Skills Tool for qualitative research (CASP) has been developed to critique qualitative studies and to assist in developing a critical stance towards the literature (<http://www.casp-uk.net/>). The CASP tool is a widely used instrument (Dixon-Woods et al. 2007) which invites the reviewer to *consider* ten critical questions. The process moves the appraiser towards making informed judgements and away from a procedural or purely technical assessment. For these reasons the CASP was chosen as a point of

reference for the critical review of the papers discussed in this chapter. However, CASP is not a definitive guide and only deals with some of the assumptions and principles of qualitative research on a broad level. Therefore, where applicable, alternative critical appraisal instruments were used to critique other forms of research inquiry, as noted in the text.

The literature review is divided into four sections; autobiographical accounts, subjective perspectives derived from the development of measurement scales and systematic reviews, quality of life research and qualitative research. The final section takes a chronological approach to reflect the development of qualitative inquiry over the last twenty five years. None of the work reviewed here specifically looked at the subjective experience of living with ataxia from a phenomenological perspective because no such work was identified from the literature search. The lack of research in this field supports the contention that the present study breaks new ground in this respect. The aim of this literature review is to demonstrate that an in-depth, experiential qualitative enquiry of progressive cerebellar ataxia is long overdue.

### **3.4.1 Autobiographical Accounts**

For the purpose of this review, autobiographical accounts of illness experience were distinguished from first-person research. Finlay (2011) described first-person research as personal accounts of lived experience where researchers critically interrogate their own experience with the intention of publishing an in-depth analysis of a particular feature of their lives. Typically, descriptive and interpretative work is undertaken; authors engage in theoretical discussion and aim to uncover new meanings that may provide insight not only about their own lives but also the lives of others. Kay Toombs' (1995; 2001) work about her own experiences of living with multiple sclerosis could be considered an exemplar of this sort of research. Literature searching uncovered no such research about the lived experience of ataxia but other types of autobiographical accounts were identified. Solicited narratives published in journals or as information leaflets published by charitable organisations were classified as forming one type of data, and unsolicited online narratives posted on blogs, message boards and membership forums formed a second class of data.

Decisions about whether a literature review should include autobiographical accounts of the type uncovered for the present study perhaps hinge on whether this sort of material is considered research as defined by the conventions set out in the Frascati Manual (Organisation for Economic Co-operation and Development, 2002). Reference to the

Frascati Manual would suggest that autobiographical accounts of this type simply represent raw material; work has to be undertaken in the form of research activity in order to acquire the new knowledge this material may possess. For example, Seale et al. (2010:595) described unsolicited personal narratives posted on the Internet as a 'repository of primary data' suitable for analysis by researchers. Furthermore, a growing number of studies about a wide variety of illness experience have exploited the Internet as a source of data on which to base research activity (see for example Bylund et al. 2005; Radin, 2006; van Uden-Kraan et al. 2008; Daker-White et al. 2011). A strict application of the Frascati definition would therefore suggest that autobiographical accounts (as opposed to first person research) should not be included in a literature review because such texts would require analysis before they could be usefully incorporated in the overall review. This rule was applied to unsolicited raw data such as that found on dedicated online ataxia platforms and forums. However, solicited narratives published by charitable organisations or in peer reviewed journals were considered as demonstrating a particular view that perhaps warranted further attention.

Five articles were identified reflecting the voices of 12 people with ataxia and two parents of children with ataxia (Drake and Guillory, 2001; Box et al. 2005; Ataxia UK, 2007a and b, and Brown, 2010). Two were written for readers with a healthcare background and were published in peer reviewed journals (Drake and Guillory, 2001 and Box et al. 2005); the remainder were published for a lay audience. All accounts were short (less than 1000 words) and were directed towards raising awareness of the progressive ataxias and the role of support groups such as Ataxia UK and the National Ataxia Foundation in the US. The accounts emphasised the early experiences of living with an ataxia as marked by uncertainty about diagnosis and a lack of understanding of the condition itself, both by those affected by ataxia as well as by healthcare professionals. In the experience of some authors (e.g. Drake and Guillory, 2001; Box et al. 2005) medical professionals emphasised the life diminishing effects of potential diagnoses and generally under-valued the role of rehabilitation and other support networks. Furthermore, whilst not underplaying negative experiences, all accounts stressed the value of maintaining a positive outlook, setting out and achieving personally meaningful goals and the role of family members and charitable organisations for providing information, peer support and other resources.

Whilst it could be argued that personal narratives may focus on issues of central concern to the authors, at the same time authors are not immune to the powerful social and cultural forces that shape other forms of narrative and self-representation. For

example, Sandaunet (2008) noted that whilst online forums (for women with breast cancer) may in theory offer alternative spaces for marginalised and minority views, there remained a tendency to discourage negative or socially undesirable comments and to preserve online communications as arenas for successful coping. The same could be said of the solicited narratives reviewed here. The message published by or written by charitable organisations and their members (sometimes members who held office) was generally optimistic. If negative experiences were reported they had, on the whole, been overcome, and the focus was on finding benefit from living with ataxia. It is also possible that these positive narratives were offered by quite privileged or advantaged people who had effective support systems. These narratives whilst interesting in themselves and valuable for those looking for information, hope and support, also perhaps left a lot unsaid. Qualitative interpretative research, by focussing on the sorts of things that provoke reflection and adjustment whilst living with a long term progressive condition, might offer a means by which possible gaps in these published narratives could be fruitfully explored.

### **3.4.2 Subjective Perspectives Derived from the Development of Ataxia Measurement Scales and Systematic Reviews**

Ataxia measurement scales have been developed for formally assessing the impact of ataxia on physical function and everyday activity, as well as a means of measuring the effectiveness of interventions for reducing ataxia symptoms (Trouillas et al. 1997; Cano et al. 2009; Morales Saute et al. 2012). During the literature search several ataxia rating scales were identified and examined to see whether the views of people living with ataxia had contributed to the development of the scale. It was anticipated that mixed method studies would include a qualitative component that elicited the views of people with ataxia about what was considered important for measuring the efficacy of an intervention. These data might have the potential to illuminate the kinds of problems people with ataxia struggled with and to bring these issues to the attention of researchers who look to develop interventions to improve life with ataxia.

Only the Friedreich's Ataxia Impact Scale (FAIS) incorporated the views of people living with ataxia as part of the process of identifying the key domains for measuring the impact of ataxia on everyday life (Cano et al. 2009). In this study, 13 people with FRA were interviewed but details of the participants, interview schedule and data analysis process were not described. Also "expert opinion" (details not provided) and information from the literature (details not provided) were used to develop the conceptual framework

for the scale. A comparison of the FAIS with other ataxia rating scales (e.g. Trouillas et al. 1997; Subramony et al. 2005 and Schmahmann et al. 2009) demonstrated commonalities in terms of measuring physical functioning but exceptionally the FAIS included other items concerned with mood, self-perception and isolation. For example, the isolation domain included questions about giving up on leisure activities, losing confidence in going out and difficulty seeing family members; domains and items that were overlooked by other measurement scales. The validity of the FAIS would bear further scrutiny in terms of the extent to which it touches upon issues significant to people living with ataxia. However, Cano et al. (2009) may have identified previously under-investigated issues and concerns in the life experience of people living with ataxia and this finding in itself would seem to strengthen the case for undertaking further in-depth qualitative exploration of this topic.

Serrano-Aguilar et al. (2009) undertook a Delphi survey of people with progressive ataxia in order to incorporate their perspectives in the design of a systematic review of the effectiveness of interventions for the progressive ataxias. The Delphi survey was reported in the same paper as the systematic review. Fifty-three participants, recruited via e-mail from patient associations in Spain, were asked in the first Delphi round to identify treatments they had used and to share their ataxia-related health problems and concerns. In the second round, health related problems were prioritised and in the final round ranking was revised in light of the individual ranking and overall ranking identified in round two. Using criteria devised to evaluate studies of this type (Sinha et al. 2011) the Delphi method used by Serrano-Aguilar et al. (2009) appeared to be methodologically sound. For example, critical features such as attrition (none), using open questions in the first round, restricting communications to e-mail to reduce contamination effects, and a clear description and presentation of the process of ranking and consensus were reported by the authors. The findings of the Delphi survey were used to inform the search strategy for the systematic review of the effectiveness of interventions i.e. the search looked for interventions that addressed concerns raised through the Delphi survey. Two important issues were identified from the results of the Delphi survey and the subsequent systematic review. Firstly, some of the identified problems that emerged from the Delphi survey (e.g. quality of life issues, trouble maintaining social relationships, difficulties with activities of daily living and psychological concerns such as loss of self-esteem) were not addressed in any of the studies evaluated for the systematic review, indicating a significant lack of knowledge and consideration of these issues by researchers developing interventions for ataxia. Secondly, the majority of participants highly valued rehabilitation whilst understanding

that it did not offer a cure. Participants in the Delphi survey viewed rehabilitation as a means of improving quality of life, self-esteem, social relationships and participation in activities of daily living. In the subsequent systematic review (same paper) only one of the twenty five selected studies evaluated the effectiveness of rehabilitation and no studies looked at psychological interventions for people living with a progressive ataxia.

There are some limitations to this work not least the brief presentation of the systematic review (for example, details about the question, protocol, search and selection criteria and overall evaluation of the selected studies were omitted) but also the potential restrictions to generalizability of the empirical Delphi survey given that the sample size was modest and restricted to members of patient associations living in Spain. Nonetheless, this study emphasised the limited advances that have been made towards understanding the subjective experience of the progressive ataxias. Serrano-Aguilar et al. (2009) offered useful insights into the concerns of people living with ataxia and the limited extent to which these concerns had been addressed by researchers. However, as an in-depth exploration of subjective experience was not the primary concern of the authors, the understanding of the lived experience of life with ataxia generated by this study remained provisional and necessarily lacked the depth and nuance that might be uncovered by phenomenological and idiographic approaches.

### **3.4.3 Quality of Life Research**

Few studies have evaluated health related quality of life for people with ataxia. The literature search identified four papers that explored this topic (D'Ambrosio et al. 1987; Abele and Klockgether, 2007; Wilson et al. 2007 and López-Bastida et al. 2008). The original paper in this series (D'Ambrosio et al. 1987) will be discussed first and then the three most recent papers will be considered together.

D'Ambrosio et al. (1987) was the first to explore the influence of impairment and disability on quality of life for people living with hereditary ataxia in Northern Italy. A questionnaire was sent out to 151 people with ataxia who were identified through hospital records. Details were lacking but an unknown number of people living with ataxia and their carers developed some of the quality of life questions for the questionnaire. These items focussed on; living arrangements (alone, with others, or institutional care), mobility (leaving the house, coping with public transport), school or work activity, frequency of contact with relatives and friends, the possibility of being accompanied by others, and recreational activities. It was unclear how these items were selected for inclusion, measured or scored. Furthermore, the disability measure used in

the questionnaire was adapted by the researchers from an independence measure for elderly people and was therefore unlikely to capture disability issues of specific relevance for people living with ataxia. In addition, the list of impairments considered relevant to quality of life was not derived from people living with ataxia but from impairments commonly observed by the researchers in clinical practice. Severity of speaking difficulty was not self-reported but scored by a neurologist and walking difficulty was reported by level of assistance required (e.g. walking stick or wheelchair use). In this respect the impairments and their significance appeared to be wholly judged by researchers or clinicians rather than the respondents themselves. This criticism aside, in the absence of an agreed definition of quality of life, the authors took steps to identify and then measure their understanding of quality of life for people living with ataxia. The main conclusion of this study was that impaired mobility was associated with reduced quality of life. However, it was impossible to determine the extent to which the content of the questionnaire resonated with the priorities, concerns and perceptions of people living with ataxia. Whilst the validity of this work remains questionable and difficult to interpret, the study represented an early attempt to involve people with ataxia in the research process. Factors that may be relevant to quality of life for people living with ataxia were identified; nonetheless the subjective, personal meaning and significance of living with ataxia remained unexplored and poorly understood.

The three most recently published papers (Abele and Klockgether, 2007; Wilson et al. 2007 and López-Bastida et al. 2008) used generic instruments to measure health related quality of life for people living with ataxia; the Medical Outcomes Study 36 Item Short Form Health Survey or the Euro-qual 5D. All explored quality of life for a progressive ataxia (sporadic progressive ataxia, FRA or SCA). Participants were drawn from Germany, Australia or Spain and sample sizes ranged from 22-84 participants. Taken together the findings from these studies indicated that people living with a progressive ataxia experienced reduced quality of life compared to healthy controls in motor domains such as physical functioning as well as non-motor domains such as social functioning, role limitation and general health perception. Wilson et al. (2007) also presented data that would caution against making simplistic inferences about the effect of severity and stage of illness as well as age of onset on quality of life. For example, individuals with mild impairment rated their quality of life similar to those with severe impairment, suggesting that ataxia had a significant impact on quality of life from symptom onset or conversely, that people learned to adjust their strategies and/or priorities over time as symptoms worsened. Participants with moderate impairment reported poorer general health, lower vitality and poorer emotional function in

comparison to those with severe impairments. The authors also found that mid-stage disease should be considered a turbulent time often experienced as a difficult period of transition and increasing dependency. Further, Wilson et al. (2007) established that whilst mental health improved with disease duration, late onset was associated with poorer quality of life, suggesting that participants may have experienced difficulty in adapting to long term progressive illness having lived a long life without illness.

The work described above offered new insights into quality of life issues for people living with ataxia and perhaps indicates the complexity of the adjustment process. However, research in stroke care has shown that generic quality of life instruments may lack specificity and may be unable to discriminate clinically important differences (Williams et al. 1999). Similar concerns prompted the call for the development of condition-specific and patient based measures capable of providing further knowledge and understanding about the impact of ataxia on quality of life (Wilson et al. 2007; López-Bastida et al. 2008). Further qualitative research should perhaps be undertaken in the first instance as an initial step towards developing more responsive and meaningful quality of life measures for people living with ataxia.

#### **3.4.4 Qualitative Research**

Interest in understanding the lives and concerns of people living with cerebellar dysfunction seems to have gone through a renaissance after a lengthy hiatus following original contributions made in the late 1980s and early 1990s. In total, seven qualitative papers were identified from the literature search that aimed to develop an in-depth understanding of different aspects of living with ataxia. This final section of the literature review critically discusses these papers, and starts by exploring the pioneering ethnographic work of Marie Boutté (1987, 1990 and 1992) before moving on to critically evaluate the remaining four papers, all published between 2009 and 2011.

Marie Boutté (1987, 1990 and 1992), in what appears to be the first study to consider cerebellar ataxia from a qualitative perspective, undertook an ethnographic comparative analysis of two separate cultural groups within which lived a population of people with Machado-Joseph disease (MJD/SCA3). The contrasting communities central to Boutté's work were a small interdependent island population in the Azorean Archipelago and what she described as a relatively anonymous population of Azorean-Portuguese ancestry in northern California. MJD is a dominantly inherited progressive ataxia first described in biomedical terms in 1972 (Nakano et al. 1972). The condition also bears a

long folk-history encompassing traditional beliefs about causality and meaning which stretches back to the mid-1800s (Boutté, 1987).

In the first of her three papers Boutté (1987) explored the meaning and configuration of stigma in the two communities. She reported the findings from 70 interviews conducted with a range of key informants, including people living with MJD but also family members, friends, doctors and community leaders. These multiple voices were used to good effect to create a vivid cultural portrait of the two communities and the people who lived there. Looking specifically at stigma and referring explicitly to Goffman's (1963) seminal work, Boutté suggested that the overall configuration of stigma was similar between the two communities but the difference lay in the weight each type of stigma carried in the two settings.

In the Azores, folk understandings were emphasised. Here MJD was labelled as a moral flaw symbolically linked with deviant sexual behaviour. People living with MJD were seen as a threat to the island's limited resources because they were (erroneously) understood as having an excessive number of children all of whom, in the islanders' view, carried the risk of MJD. It was commonly believed that these children would become physically dependent, unable to work and, because of their care needs, would further deplete the number of farm labourers available for the type of work critical to sustaining the local economy. In response to these beliefs, the islanders adopted containment and confinement strategies through proscribing marriage and espousing eugenic ideologies such as the sterilisation of people with MJD. In California, the "moral flaw" associated with the "stumbling disease" was placed in a more general stigmatising category related to inebriation. People with MJD were subsumed into a broader class of people tainted with the label of alcohol abuse or dependency which appeared to carry less weight than the labelling used in the Azores in response to the same stigmatising typology. Furthermore, Boutté described what she saw as greater opportunities to mitigate stigmatising labels in the United States when compared to the situation in the Azores, e.g. by self-labelling with a non-hereditary disorder such as multiple sclerosis. Such options were not available to those in the Azores who, by living in a less anonymous community, were effectively labelled and treated as "deviant" from birth.

Boutté's second and third papers (1990, 1992) were directed towards understanding the subjective experience and cultural construction of genetic threat in the context of the family and the communities in which the families lived. The first of these papers explored the perspectives of participants in the northern Californian setting who were at risk but yet to manifest symptoms of MJD. Of the 20 people interviewed 18 were at risk of

developing MJD and were therefore able to provide a personal and particularised account of the lived experience of genetic risk. In reporting the findings Boutté identified how personal and cultural beliefs became intermingled with objective biomedical information to produce a multidimensional and mutable conception of risk which was only weakly associated with statistical probability. Family dynamics varied and did not lend themselves to the development of simple predictive models that might anticipate behaviours in response to disclosure of risk. In this cultural setting personal and folk-beliefs about genetic threat were not fundamentally altered by the newly emerging biomedical evidence of risk. Boutté emphasised that the logic associated with genetic testing (biomedicine) carried with it objective assumptions about risk. These assumptions did not hold true when brought up against subjective needs and real life concerns about the meaning of risk or a positive or negative test in the context of individual lives. In other words, participants' perception of genetic threat was only partially informed by advances in biomedicine, and previously held beliefs continued to shape their understanding of their hereditary risk.

Boutté's final paper in the series (1992) maintained the focus on understanding genetic threat but from the Azorean perspective. The findings conveyed the ways in which perceived genetic threat shaped family dynamics and identities as well as kinship networks and interactions with the larger island community. Persistent folk models unchanged by biomedical advances continued to inform the islanders' understanding of MJD. Syphilis and incest were cited most frequently as underlying causative factors. People living with MJD were therefore denied status, became the subject of gossip and, in this paternalistic society, women continued to be encouraged by medical and social service representatives to be sterilised. As a "family disease", people at risk of or living with MJD were treated similarly; both threatened the social status of the family and kinship relations. Women in particular who were no longer able to fulfil traditional roles (running the home, caring for children as well as working on the farm) were resented for being an additional burden of care, shamed for not being able to participate in expected reciprocities (between and within kinships) and were blamed for impoverishing the nuclear family and diminishing its status within the island community. The meanings ascribed to MJD and the behaviours adopted towards those living with or at risk of MJD appeared entrenched and efforts to organise support groups along similar lines to those set up in the US foundered due to lack of community support and ineffective, poorly resourced and fragmented social services.

As befits an ethnographic study, Boutté immersed herself in the local culture; she carried out extended observations of day to day life in the two communities in addition to conducting in-depth interviews in the either Portuguese or English. However, with only four of the 62 quotations in the three papers coming from people living with MJD there was little focus on the personal lived experience of this type of ataxia. Furthermore, it seemed that of the people with MJD who were interviewed only about half agreed to be tape recorded. Hand-written notes raise questions about the completeness and accuracy of the record (Creswell, 2007) and may also account for the relative lack of direct quotations about the subjective experience of MJD in Boutté's work. In addition, perhaps reflecting the time in which these papers were published, as well as journal word count restrictions, there was little detail provided about the process of analysis. Contemporaneous criteria for "good" ethnography valued careful fieldwork (Spindler and Spindler, 1987) and seemed to pay less attention to analysis, reflexivity and the position of the researcher in the research; essential criteria by current standards (Creswell, 2007) but absent from Boutté's work. Therefore it was difficult to judge how the data were analysed and the extent to which Boutté's own cultural references were brought to bear upon the data collection and analysis of the presented findings.

Despite its shortcomings, Boutté's (1997) work demonstrated the powerful influence that stigma and perceived genetic threat may exercise in small communities. The findings from these three studies were highly situated to the cultures, values, beliefs and language of both the setting and the epoch. They told little of the personal lived experience of MJD but conveyed an insightful, if at times disturbing, picture of its symbolic meaning and the ways in which the two cultural groups behaved towards, classified and responded to people living with or at risk of developing this condition. Nonetheless, Boutté conducted her study over twenty five years ago, much of the biomedical framework has moved on rapidly and in the intervening period cultural beliefs and contexts may have changed. Ataxia could be lived and experienced very differently in twenty first century UK compared to the late twentieth century perspective of people living in the US and the Azores. This would suggest that aspects of Boutté's work could be usefully updated and placed within a UK context. Furthermore, as the personal perspective of living with MJD was only partially addressed in Boutté's work, research which attends more closely to personal meaning and significance would perhaps provide a voice for those who live with MJD or similar ataxic conditions.

Having considered Boutté's work in depth, this section now moves on to critically review the more recent contributions to qualitative research in this field. Walshe and Miller

(2011) conducted in-depth interviews to explore the experience of living with dysarthria and to develop an understanding of the impact of dysarthria on psychosocial function. Of the 11 participants, four were living with dysarthria as a result of cerebellar dysfunction. Although not forming the majority of the sample, 54% of the quotations used to illustrate the findings were derived from participants with cerebellar dysarthria. Furthermore, the experiences of people living with cerebellar dysarthria were represented in each of the emergent themes. It is suggested therefore that the findings from this study might provide some insight into the particular experiences of people living with dysarthria as a result of cerebellar dysfunction.

Theoretical sampling was used to select potential participants so that a range of people of different ages and with a variety of neurological conditions as well as severity and experience of dysarthria (those concerned about their dysarthria as well as those who reported no concerns) were recruited. Interviews were transcribed verbatim and Framework Analysis (Ritchie and Spencer, 1994) was used to analyse the data. The decision to use Framework Analysis rather than perhaps a more appropriate phenomenological approach was not discussed in the paper. Nonetheless, the findings were grounded in the participants' accounts and several quotations were used to illustrate each theme. Readers were therefore able to judge and thereby have some confidence in the credibility of the findings. An independent observer coded a sample of the transcripts to reduce bias, similar findings were reported which were said to provide a measure of reliability and verification of the first indexing process. No further details were supplied about data analysis or the means by which the two authors achieved consensus.

Walshe and Miller (2011) argued that the key findings of their work specifically highlighted that the impact of dysarthria did not relate in any straight forward way to the severity of impairment and was highly individualised. The particularised experience of individuals was stressed as the *locus operandi* for clinical practice and it was here that the inclusion of people for whom dysarthria was not reported as problematic worked well: similar experiences were interpreted and made meaningful and significant in different ways depending on individual perspectives. However, a more in-depth exploration of participants' experiences could have been achieved if a phenomenological approach had been taken. For example, further attention could be paid to particularised accounts to develop a better understanding of the embodied experience of dysarthria (specifically – as noted by the authors – to further explore the interrelated nature of dysarthria and other physical impairments and their joint impact on

psychosocial function) and the impact of dysarthria on a person's sense of identity. Despite these shortcomings, the authors achieved their objectives and presented common themes identified by the majority of participants: reduced confidence and feelings of inadequacy, a heightened awareness of the assumptions and negative evaluations of others, and the development of strategies to manage or overcome communication barriers. Whilst recognising the limitations of the study, the authors identified appropriate areas for intervention, stressing the importance of psychosocial as well as impairment based approaches to dysarthria. Overall the authors identified that dysarthria impacted on multiple dimensions of experience. Whilst these findings may hold some relevance for people living with cerebellar ataxia, Walshe and Miller (2011) provided only a glimpse into the broader experience of living with this complex condition, a glimpse that would perhaps lend itself to a fuller phenomenological exploration.

As discussed in the introductory chapter, advances in molecular genetics have enabled the development of DNA tests to detect gene mutations responsible for some late-onset neurodegenerative conditions. International protocols have been developed to establish standards for counselling services for people undergoing pre-symptomatic or predictive testing for conditions such as hereditary ataxia and Huntington's disease (see for example Goizet et al. 2002; Smith et al. 2002; Paneque et al. 2007 and Cruz Mariño et al. 2011). However, little work has been carried out to understand the experience of diagnostic DNA testing for individuals who already have symptoms of neurogenetic conditions. In response to the lack of qualitative research on this topic, Hess et al. (2009), in what appears to be the first study of this type in this field, explored the meaning of actual or potential DNA testing and the experience of the familial, social and economic implications of genetic tests for people living with the signs of Huntington's disease (HD) or genetic ataxia. In-depth interviews with 27 participants (13 with ataxia) recruited from neurology clinics in Southern California were undertaken.

A critical analysis of Hess et al. (2009) identified a number of methodological issues primarily concerned with the extent to which the experiences of individuals were explored and the ways in which the data were analysed and reported. For example, content analysis was undertaken on the transcribed accounts to identify patterns and key topics, no further information was provided to determine how this work was undertaken, information was also lacking about how the four themes presented in the findings were identified and the extent to which each participant contributed to each theme. Furthermore, the authors described using a case study approach to understand how genetic information was evaluated with reference to disease progression and work

status but no further information was provided about how this case study was undertaken or incorporated in the findings. Nine quotations were used to illustrate all themes, only one of these was from a participant living with ataxia. Observational data from 27 neurology clinic consultations were also collected for this study but no details were provided as to how these data were included in the analysis or development of the findings.

Despite these methodological concerns, this study was the first to explore the meaning of DNA testing for people with hereditary ataxia and provided some useful insights into this complex topic. The authors reported that genetic testing was viewed in a positive light for most participants because it represented a welcome end to years of living with diagnostic uncertainty and tiresome consultations, and the start of gaining some sense of control over their condition. However, the authors reported that unambiguous information about the purpose and implications of each test was rarely provided and misunderstandings about the value of a positive test were commonly reported. Participants assumed that, once diagnosed, a treatment would be available that could slow down or stop illness progression. Furthermore participants were unaware that a negative test result excluding one type of genetic disorder did not necessarily eliminate other progressive hereditary conditions. Genetic counselling did not form part of the pre- or post- testing process for the majority of participants. Facing an unexpected genetic condition without the sort of preparation offered through specialised genetic counsellors left many participants who lacked a known family history of the illness ill-equipped to cope with the personal, family and social consequences of a positive test. In contrast, for participants with previously diagnosed family members, individual circumstances impacted on their responses to a positive test which ranged from relative acceptance to extreme distress. The findings suggested that participants were better placed to cope with a definitive diagnosis if they had experienced symptoms for several years, were able to access effective support systems, were retired and already had children.

Although Hess et al. (2009) tell little of the specific experiences of people living with ataxia, this paper provided another glimpse into issues that would seem to be significant for people living with this condition. Nonetheless, HD differs from cerebellar ataxia particularly with reference to the psychiatric and cognitive disorders that significantly impair social and occupational function and often herald the first signs of HD (Leroi et al. 2002). The impact of a positive test result for people diagnosed with HD may possibly be more distressing or have more immediate consequences than for people living with ataxia. In addition, HD can be confirmed by a repeat blood test (Huntingdon's Disease

Collaborative Research Group, 1993) whereas DNA testing is only available for some of the ataxia subtypes (Tan and Ashizawa, 2001; Paulson, 2002; Schöls et al. 2004; Finsterer, 2009). This would suggest that although there may be similarities between HD and progressive cerebellar ataxia, the situation is not the same and this would question the validity of exploring the experience of genetic testing for both conditions at the same time.

In the penultimate paper discussed in this review, White et al. (2010) argued that little was known about the psychological or psychosocial effects of Friedreich's ataxia (FRA); specifically the transitional life events brought about or altered by FRA and the impact of these events on an individual's life experience. Semi-structured interviews were undertaken with 42 adults with FRA (18-65 years) about their perceptions of transitional life events. Participants were recruited from membership groups for people with ataxia or neurogenetic conditions. Data were analysed using Template Analysis (Crabtree and Miller, 1992), a third of the transcripts were coded by a second analyst and good inter-coder reliability was demonstrated, no further information was provided about the development of themes. Perspectives from both genders were equally represented and a sufficient number of quotations were used in the presentation of findings for the reader to have confidence in the claims made by the authors. The authors acknowledged the selection bias inherent in their sample and indicated limitations regarding generalisability of the findings. One criticism levelled at this study concerns the limited way in which the researchers examined their own role in data collection and analysis and the potential influence their reading of the data may have brought to the findings. Furthermore, readers were unable to access the interview schedule either within the paper or via electronic supplements to the published data, it was therefore impossible to judge the extent to which the interview was participant-focussed rather than researcher-driven.

The findings of this study suggested firstly, that FRA altered developmentally-related life transitions such as dating, marriage, parenting and occupation. Secondly, a series of temporal transitions corresponding to clinical progression of the signs and symptoms of FRA also characterised the experience. Symptoms recognition was identified as one of these significant temporal transitions and was considered more significant than diagnosis. Impaired mobility status and fear of falling formed a further transitional event that was commonly accompanied by actual or perceived stigma which in turn challenged participants' sense of identity and self-esteem. Finally, the transition represented by the use of assistive walking devices and wheelchairs progressed from initially representing diminished independence and further stigmatisation to being seen as a means of

promoting freedom and self-sufficiency. Overall FRA magnified the significance and increased the complexity of commonly experienced transitional life events.

Unique to the body of work reviewed thus far, the authors argued that people living with FRA faced an almost continual adjustment to change and experienced only limited periods of stability compared to those who live without progressive illness. Recommendations were made for genetic counselling to prepare patients for significant transitions, to support the development and preservation of self-identity and to restore meaning and control in the face of living with a progressive condition. Whilst these recommendations may be relevant for genetic counsellors (reflecting the professional interests of the authors) they also seemed salient for all healthcare professionals who may encounter people coping with the physical and psychological consequences of FRA. White et al. (2010) therefore extended the understanding of the impact of transitional life events for people living with FRA and supported the findings of Wilson et al. (2007). As White et al. (2010) focussed specifically on the experience of people living with FRA, their work could perhaps be usefully extended to look at whether people with other types of progressive ataxia face similar issues.

In the final paper reviewed in this section, Daker-White et al. (2011) focussed on the experience of the diagnostic process for people living with a progressive ataxia. This study examined data derived from international English language Internet discussion forums created specifically for people living with ataxia. The majority of data was drawn from the US (50%) and the UK (40%) over an unknown period of time, and was estimated to represent communications of varying length from just over one hundred individuals. The authors argued that because progressive ataxia is a rare condition, internet data served as a useful proxy for data gathered in an interview situation; the assumption being that participants would be difficult to recruit and may prefer to use Internet forums as a means of communicating with others. With reference to Robinson (2001), the authors further argued that unsolicited internet narratives offered a rich source of qualitative data and provided insights that would not be elicited from face-to-face interviews. Both arguments would bear further scrutiny before discussing the findings of this study.

Seale et al. (2010) conducted a comparative analysis of the characteristics of qualitative research interviews (alongside video recording for [healthtalkonline.org](http://healthtalkonline.org)) and archived Internet discussion forum postings and e-mail queries, to evaluate their usefulness as data sources about the experience of illness (namely breast cancer, prostate cancer and teenage sexual health problems). The findings suggested that participants in each

format (interview or online) had radically different orientations. Those in the interviews constructed a narrative that was oriented towards the past and present, whereas those who participated in Internet communication were orientated towards the immediate future. Seale et al. (2010:600) claimed that participants who posted on the Internet were 'doing their illness in the here and now' as they exchanged technical (biomedical) and practical information and support, whereas those who were interviewed 'enacted' their experiences through reflection and 'narrative self-construction'. The authors identified however, that the apparent focus on past events may have been an artefact of producing data for healthtalkonline.org; interview participants were asked to tell their stories, an approach that might be expected to prompt reflection through narrative reconstruction. In addition, whilst the researchers found that disclosure of sensitive topics was facilitated through the anonymity provided by Internet forums, they also conceded that interviews conducted by skilful and experienced practitioners were also capable of eliciting rich, contextualised descriptions that were not found in the fragments of experience offered on the Internet (Seale et al. 2010). Overall, the findings from this study seemed to suggest that interviews and on line forums offered very different data which reflected the distinct intentions and contexts of the participants in each setting. It would be naïve to suggest that unsolicited online data offers unproblematic and transparent access to experiential narratives and therefore the assertion that data gathered from internet forums offer a valid proxy for qualitative interviewing could be disputed.

Returning to Daker-White et al. (2011), and in light of the critique that could be levelled at its original premise (online data as substitute for interview data), it was noted that the authors considered some of the limitations of the methods used in this study, in particular the inability to probe themes more deeply, the likelihood of the sample representing the views of those who experienced a problematic diagnostic process, as well as the ethically questionable approach of covertly collecting data without consent (issues discussed in-depth by Seale et al. 2010 and O'Brien and Clark, 2012). Similar to the findings described by Hess et al. (2009), Daker-White et al. (2011) detailed a lengthy, wearisome and frustrating process of diagnosis; the importance placed on having a definitive diagnosis and of putting an end to contested illness identities. In particular, Daker-White et al. (2011) called attention to the participants' understanding of a diagnosis of idiopathic ataxia as being equivalent to no diagnosis at all. The authors pointed out that most people (nearly two-thirds) who posted comments had an ataxia of no known origin. This "non-diagnosis" seemed to compound the sense of uncertainty reflected in their posts and prompted a critical evaluation of the expert status of medical

practitioners. Daker-White et al. (2011) further argued that at a certain point in the diagnostic process participants underwent a shift in perspective. Instead of focussing on finding a cause for their particular ataxia and a definitive diagnosis, they turned towards finding ways of living with ataxia. However, as some forums were searched specifically for posts about diagnosis rather than learning to live with ataxia, the authors admitted that this was a tentative argument that required further investigation.

In addition to the findings discussed above, the study also illustrated that unknowingly passing on a genetic condition was a troubling and on-going concern. Powell et al. (2010) reported similar findings in their investigation of the impact of patents on access and referral to genetic testing for spinocerebellar ataxia. This paper is not discussed in detail in this review because its emphasis was on the effect and cost of genetic testing patents in the US rather than subjective experiences. Nonetheless, in support of the findings of Daker-White et al. (2011), the authors further emphasised the complex and troubling emotions associated with both positive and negative test results as well as the importance placed on putting an end to uncertainty. Taken together, the findings from Hess et al. (2009), Powell et al. (2010) and Daker-White et al. (2011) seemed to point towards an emerging picture. The intermingling of folk understandings with biomedicine as a culturally constructed way of understanding ataxia, as put forward by Boutté (1992), may have been replaced by a stronger biomedical orientation characterised by uncertainty and misunderstandings about the new genetics. Rather than providing clarity, the complex and often uncertain diagnostic process seemed in all three papers reviewed above to fall short of providing the answers that people with ataxia were looking for.

In summary, Daker-White et al. (2011) failed to fully discuss their theoretical orientation towards the data used in this study (i.e. whether the analysis was informed by realist or constructivist perspectives) as well as the limitations of carrying out an experiential analysis on data that might have been particularly concerned with the “here and now” (Searle et al. 2010). Whilst this work is not fundamentally flawed, it lacks the contextual contouring that usually accompanies interview studies which, in addition, not only offer a means of eliciting richer accounts but also the opportunity to explore different moments in time of significance to participants. Daker-White (2011:132) acknowledged that this study represented only the first step towards understanding the utility of diagnostic testing for people with ataxia and stressed that a clearer understanding of these complex issues would only emerge when ‘the lens is moved away from the diagnosis process to the illness and healthcare experience more generally.’ This judgement of

their own work also perhaps reflects the limitations of the rather fragmentary work that has been undertaken to date in this field and lays the foundation for a more in-depth exploration of the lives and experiences of people living with a progressive ataxia.

### **3.5 Summary**

This review of the literature explored a rather disparate body of work published between 1987-2011 which, in itself, has made some progress towards understanding how people encounter and make sense of in their lives with ataxia. Solicited personal narratives (Drake and Guillory, 2001; Box et al. 2005; Ataxia UK, 2007a and b, and Brown, 2010) focussed primarily on the diagnostic process and, in general, broadcast a rather optimistic picture. This somewhat partial view provoked critical questions about what had been left out of these possibly quite privileged accounts which in turn strengthened the call for further qualitative research in this field. Qualitative work undertaken as part of larger quantitative studies (Cano et al. 2009 and Serrano-Aguilar, 2009) identified that most intervention based studies did not attend to issues and concerns identified by people with ataxia. Without further research to develop a fuller understanding of what matters to people with ataxia, there is a risk that intervention based studies will continue to be researcher-focussed and as such abstracted from the everyday lives and concerns of people living with ataxia. Working from different but complementary perspectives, Wilson et al. (2007) and White et al. (2010) provided novel insights about the impact of transitional events on the lives of people living with FRA. This work cautioned against making simple inferences about the significance and meaning of commonly collected clinical data (such as age, symptom severity and years since onset) and, by doing so, perhaps strengthened the case for undertaking in-depth qualitative work in this field.

Boutté's original ethnographic study (1987, 1990 and 1992) provided the fullest and most contextualised account of the meaning and significance of MJD however, the subjective experiences of people living with this condition were not well represented in the data or the discussion of the findings. Walshe's and Miller's (2011) study about the impact of dysarthria on psychosocial function afforded a small glimpse into the issues, concerns and burdens associated with managing communication difficulties in public and private. The experiences of people with ataxia were under-reported in the published account, and as the focus was on dysarthria, the impact of other impairments was left unexplored and incompletely understood. Hess et al. (2009) presented findings that also offered just a small glimpse into the challenges and complexities of living with a condition that carries genetic and diagnostic uncertainties (HD and genetic ataxia).

However, as HD and the genetic ataxias are different conditions, with quite separate illness trajectories and expectations, it is argued here that they should perhaps be treated separately in future research. In this way the particular issues associated with genetic testing for each of the conditions might be more thoroughly understood. Finally, the review of Daker-White et al. (2011) raised concerns about the treatment of online discussion forums as equivalent to the sort of experiential data that might be collected via in-depth interviewing. Nonetheless, this work identified similar concerns to Hess et al. (2011) and Powell et al. (2010) about the arduous process connected with the diagnosis of progressive cerebellar ataxia. Further qualitative research that aims to explore the impact and meaning of the diagnostic process for people living with a progressive ataxia may be well placed to shed further light on what seems to be a significant issue for people living with this condition.

Taken together the reviewed work perhaps provides just fragments of insight and understanding about this complex condition. None of the qualitative studies were phenomenological in their orientation and therefore none of the authors approached their work with the intention of understanding life with ataxia in a phenomenological sense. In other words, there was no attempt to make the 'special effort' required to understand the perspectives and contexts of another person's experience (Gadamer, 2004 [1960]:304). Therefore, although the majority of the work reviewed in this chapter was published whilst the present study was in progress, the lived experience of ataxia remained only faintly illuminated. In particular, from this author's perspective, the absence of any examination of the embodied experience of ataxia and healthcare in general signified an important gap about what is known and understood about this condition. Thus, the case could be made for undertaking further qualitative research about the lived experience of progressive cerebellar ataxia. Phenomenological enquiry would offer a means of going beyond what is ordinarily understood about life with ataxia, not only in terms of exploring the lived body but also in terms of gaining an in-depth, nuanced and finely grained appreciation of individuals and their world; a perspective that seems to have been neglected in previous work.

### **3.6 Conclusion**

In summary, the key emerging themes from this review of the literature seem to indicate uncertainty and confusion about the diagnostic process and genetic testing. Furthermore, unlike other long term conditions (as discussed in chapter 2), the experience of healthcare more generally for people living with progressive cerebellar

ataxia has yet to be explored in any depth. Primarily negative psychosocial implications and the life diminishing aspects of cerebellar ataxia were also emphasised in the literature discussed above. White et al. (2010) perhaps offered the most nuanced and in-depth exploration of FRA. These authors called attention to the co-existence and added complexity of condition-specific transitional events (such as the emergence of symptoms, or the use of assistive walking devices) and developmental life events (e.g. dating, starting work) in shaping the experience of people living with FRA and particularly highlighted instability as a significant feature of life with this condition. Nonetheless, the literature concerned with exploring and understanding life with progressive ataxia has produced just fragments of insight, glimpses into the lived experiences of this complex and rare condition. Therefore it is argued here that further research designed to explore the subjective experience of people living with progressive ataxia is long overdue. Phenomenological work, directed towards understanding the lives of individuals in the fullness of the contexts that are meaningful to them would enhance previous work in this field. An idiographic approach has the potential to reach to the deeper meaning of individuals' experiences whilst connecting with that which may be shared (Smith et al. 2009). Such work may therefore speak for the general as well as the particular and by doing so prompt others to consider the possible implications for their own work (Johnson, 1997). This latter point, the potential for theoretical generalisability, formed an important strand in the development of this study. It is the reason why the research questions focussed not only on the lived experience of progressive ataxia but also the experiences of healthcare, and physiotherapy and physiotherapy services in particular.

### **3.7 Research Questions**

The arguments presented in this chapter have continued to build a case for understanding more about the lived experience of progressive cerebellar ataxia. Thus the research questions introduced in chapter 1 have been further justified in this and the preceding chapter and have been defended with respect to gaps identified in the literature.

1. What is the meaning of progressive cerebellar ataxia for people who live with this condition?
2. How do people living with a progressive cerebellar ataxia experience healthcare, and physiotherapy in particular?

3. What is the meaning of exercise and activity participation for people living with progressive cerebellar ataxia?

The following chapter details the methodological approach taken towards designing and carrying out this study.

## **Chapter 4**

### **Methodology**

#### **4.1 Introduction**

This chapter introduces Interpretative Phenomenological Analysis (IPA) and argues that IPA is an appropriate method for answering the research questions identified for this study.

Unlike research into other progressive neurological conditions, ataxia has been almost exclusively understood from a biomedical and quantitative perspective. As chapter 3 demonstrated, when this study commenced in 2006, only limited qualitative work had been undertaken about people's experiences of living with cerebellar ataxia. From this rather unsatisfactory position, further research in this field could have proceeded in several directions (either quantitative or qualitative). However, for this researcher, it was the absence of an insider's view of the experience of living with ataxia that was most compelling. Further quantitative rehabilitation research undertaken without consideration of the multidimensional perspectives of a person's experience of a health condition might be ill informed and potentially compromised by narrow and underdeveloped ideas (Mattingly, 1993; Shepard et al. 1993; Kearney, 2001; Curry et al. 2009). It would also be out of step with current guidance to consider patients' views (for example the UK based Research for Patient Benefit Programme, National Institute for Health Research, 2008). For these reasons an inductive, qualitative approach to addressing the research questions seemed to be a valid and relevant starting point for further research in this field.

This chapter firstly introduces IPA and places the present study within this evolving field of qualitative enquiry. The main content of this chapter sets out to justify IPA as an appropriate methodology for exploring the lived experience of cerebellar ataxia. It does this by explaining the theoretical underpinnings of IPA in some depth. The ethical dimension of investigating and interpreting another person's experience is then briefly considered before moving on to clarifying IPA's epistemological and ontological assumptions. Other phenomenological methods are considered within the later sections and the reasons for not adopting these approaches are discussed.

## 4.2 Interpretative Phenomenological Analysis

IPA is a qualitative research methodology oriented towards exploring and understanding how people make sense of particular life experiences (Smith et al. 2009). IPA's understanding of an experience in this sense is aligned to Dilthey's definition of an experience as a 'comprehensive unit', something of significance, a part or parts of a life connected by a common meaning (1976 [1910]:210). IPA typically explores the things that matter to people in their lives, events for example that provoke reflection and emotional or psychological adjustment (Eatough and Smith, 2008). IPA research is therefore specifically interested in 'lived experience'; everyday life and what it is like when a part or parts of that life take on particular meaning (Smith et al. 2009:1).

Consistent with other phenomenological approaches, IPA understands that subjective experience or consciousness is directed out into the world. In other words, individuals are always conscious of something (Smith et al. 2009). The phenomenological term for this is intentionality (Husserl, 2001 [1921]). For example, individuals may love, fear, think, perceive, remember or judge but there is always an intentional object associated with this act; people fear something, think about something, and remember something in their world of experience (Zahavi, 2003). IPA concerns itself with all aspects of this lived experience 'from an individual's wishes, desires, feelings, motivations, belief systems through to how these manifest themselves or not in behaviour and action' (Eatough and Smith, 2008:181). IPA therefore involves the detailed examination of peoples' lives; their day to day experiences, how they have made sense of those experiences and the meanings they attach to them (Smith, 2004; Smith et al. 2009). The findings from such research may illuminate particular facets of human existence that in the everyday flow of life are normally taken-for-granted. These include the embodied, sociocultural, temporal, spatial and intersubjective contexts that constitute a person's experience of the world, known phenomenologically as the 'lifeworld' (Finlay, 2011:19).

Ultimately, IPA aims to do research that is 'experience-close' (Smith et al. 2009:33). Researchers seek to provide a multidimensional understanding of a person's lived experience that goes beyond an everyday or common sense awareness. The findings from IPA research are therefore highly nuanced and offer a fine grained analysis that can be used to contextualise existing quantitative research, to inform understanding of novel or under-researched topics or, in their own right, to provoke a reappraisal of what is considered known about a specified phenomenon (Smith et al. 2009).

### **4.3 Theoretical Perspectives of IPA**

The key theoretical perspectives of IPA are; phenomenology, interpretation (hermeneutics) and idiography (Smith, 2004, 2007; Smith et al. 2009). These features are not unique to IPA, but the way in which they have been combined and the specific emphases and techniques used within the method identify IPA as an affiliated but distinct approach in the field of phenomenological enquiry (Smith, 2004; Smith et al. 2009). This next section discusses these three foundational components and highlights their relevance to the present study.

#### **4.3.1 Phenomenology**

Phenomenology is both a philosophy and a set of research methods concerned with exploring and understanding human experience (Langdrige, 2007). Phenomenology develops knowledge through the study of phenomena; things or events in everyday life. 'Things' are understood, as far as possible, in the way they appear, or in phenomenological terms, the way they are 'given' to the experiencing person (Zahavi, 2003:12). A phenomenologist is interested in *how* a phenomenon is experienced, the manner in which it is experienced, rather than looking towards explanations of *what* constitutes the phenomenon (Cox, 2008).

Phenomenological philosophy has gone through several elaborations as successive philosophers have engaged with it, interpreted it and taken it in different directions. Phenomenology is therefore best considered a movement rather than a prescribed method or system (Moran, 2000). Similarly, phenomenological research, whilst retaining a fundamental interest in human experience, has also developed in several directions depending upon the particular philosophical approach underpinning the inquiry (Creswell, 2007).

IPA's reading of phenomenology is anchored to the work of four major philosophical figures; Husserl, Heidegger, Merleau-Ponty and Sartre (Smith et al. 2009). This next section briefly sketches out the critical thought of these key authors, explores how their perspectives have been incorporated within IPA, and identifies their particular relevance to this study.

##### **4.3.1.1 Husserlian Phenomenology**

The contemporary understanding of phenomenology emerged from the work of the German philosopher Edmund Husserl (1859-1938), (Moran, 2000). Husserl's work is of

significance to IPA because it established the importance of a careful and methodical focus on human lived experience (Smith et al. 2009). Producing his most influential work in the early decades of the Twentieth century, Husserl argued that the prevalent positivist tone of scientific enquiry failed to address fundamental questions about the meaning of human existence (Dahlberg et al. 2008; Moran, 2000):

‘... this science has nothing to say to us. It excludes in principle precisely the questions which man, given over in our unhappy times to the most portentous upheavals, finds the most burning: questions of the meaning or meaninglessness of the whole of this human existence’ (Husserl, 1970 [1954]:6).

According to Husserl, scientific and objective views of the world were abstracted from ordinary (lived) experience, and therefore provided a distorted and impoverished understanding not only of the world but also of the experience of humans in the world (Moran, 2000; Dahlberg et al. 2008).

For Husserl, knowledge not grounded in subjective experience was absurd or meaningless (Husserl, 1982 [1913]). He did not deny the importance of objective knowledge, but argued that “things” in the world (abstract and concrete) were always experienced by a perceiving subject, and from a particular perspective or point of view. These perceptions were necessarily influenced by scientific and lay concepts such as hypotheses, expectations and assumptions (Rennie, 1999; Moran, 2000). In this sense, Husserl argued that reality, or things in the world, did not “speak for themselves” but were articulated or made possible by an experiencing subject (Husserl, 1970 [1954]). Therefore rather than artificially removing the human perspective, Husserl argued that if the world was to be understood it must include an understanding of the relation between human beings and their world (Moran, 2000; Dahlberg et al. 2008).

In other words, human consciousness allows there to be a world in the first place, not because consciousness creates the world but because it makes the world meaningful. Knowledge of something (including logical or scientific knowledge) is therefore presupposed in consciousness and, for Husserl, the only way to understand a particular phenomenon was to set aside (or bracket) the distorting and inhibiting influences of the natural suppositions of everyday life or everyday consciousness (Moran, 2000). These assumptions are what Husserl termed the natural attitude, the conventional view of the world and other scientific, philosophical and cultural ways of understanding human existence (Husserl, 1970 [1954]). Husserl’s position in this respect is neatly summed up by Zahavi (2003:45) ‘We keep the attitude (in order to be able to investigate it) but we

bracket its validity'. Put differently, knowledge is not achieved by abandoning what we think we know but by taking a different attitude towards it; adopting a phenomenological attitude rather than a natural attitude.

Husserl therefore advocated phenomenology firstly as a means of going beyond what theoretical (scientific) conceptions and everyday taken-for-granted assumptions of the world were capable of explaining or understanding, and secondly as a means of securing the lifeworld of human existence as the foundational core for all science and all knowledge (Rennie, 1999; Moran, 2000; Dahlberg et al. 2008). For Husserl, lifeworld refers to the taken-for-granted 'structure' of the world of ordinary experience: the 'simple, straightforward and ongoing life' (Husserl, 1970 [1954]:139,144).

Husserl's aim was to access the pure essence of human experience, the content of consciousness itself (Moran, 2000). He developed a way of looking at the things of experience called the epoché. This is the process that brackets out or suspends the unquestioned and inauthentic acceptance of everyday experience, and, via a series of steps called the reduction(s), permits access to the experiential content of consciousness (Husserl, 1927; Moran, 2000; Zahavi, 2003). It seems that Husserl chose the word 'reduction' carefully, not simply to give a label to the conceptual process he described but also because it was derived from the Latin *reducere*, meaning 'to lead back to' (Moran, 2000:146; Zahavi, 2003:46). Husserl's objective was to 'go back to the things themselves' (Husserl, 2001 [1913]:168), i.e. the experiential content of consciousness without the distorting influence of conventional understanding (Moran, 2000; Zahavi, 2003). The epoché and the reduction(s) led the way back to, or recalled, the things of experience by inhibiting 'every judgemental drawing-in of the world' (Husserl, 1927:4). Husserl (1970 [1954]:144) argued that this special kind of phenomenological reflection 'breaks through the normality of straightforward living'. He further reasoned that if a person was able to identify the essential structures of their own experience by using this method, then a progression of the reduction might lead to an understanding that could transcend the individual and go on to identify the general structures of consciousness itself (Moran, 2000).

It should be noted that the prevalent view of Husserl's interest as being directed towards understanding consciousness from a purely disembodied and unworldly perspective appears outdated (Zahavi, 2003; Larkin et al. 2006) and it is not the intention of this outline to propagate this reading of Husserl's work. Zahavi (2003:46) carefully argued that Husserl's epoché and the reductions should not be considered as a turning inwards

towards a transcendental consciousness, an act of introspection, but as an opening out, an 'expansion' of the field of research. Husserl was interested in consciousness because for him it was only in consciousness that something could appear, and only by reflecting upon the way something appears to consciousness, without prejudice, would it be possible to understand what it is to know something, a way of knowing that is normally obscured by the natural attitude. The epoché changes the way in which a person approaches reality rather than excluding reality from the field of research (Zahavi, 2003). A phenomenological investigation should therefore open up a new way of experiencing and theorizing that is not constrained by commonsensical ways of seeing the world.

In contrast to Husserl's focus on consciousness, IPA seeks, perhaps more concretely, to understand particular experiences as embedded in the lifeworlds of particular individuals and only cautiously makes more general claims (Smith et al. 1995; Smith and Osborn, 2008; Smith et al. 2009). Despite the attenuation of the scope of the phenomenological project as envisioned by Husserl, his ideas continue to inform contemporary phenomenological enquiry and IPA in particular. Husserl established the importance of phenomenology as a means of restoring the human perspective to scientific enquiry and identified human experience as a rich and genuine source of knowledge. Furthermore, Husserl's concept of the epoché forms a critical concept for phenomenological health research (Finlay, 2008, 1999). The way in which these projects are carried out and even the feasibility of bracketing in its Husserlian sense continues to be a matter of debate (LeVasseur, 2003; Gearing, 2004; Finlay, 2008, 2011). However, the importance of developing and acknowledging an awareness of, and reflecting upon, one's own assumptions and habitual ways of thinking continues to be a central concern of IPA and of phenomenologically informed enquiry more generally (Finlay, 1999, 2008, 2011; Smith et al. 2009, Shaw, 2010). In this regard, IPA should perhaps be understood as a careful and rigorous research enterprise undertaken with reference to Husserl's ideas about reflecting upon prior understandings, rather than using his exact "methods" or ultimate aims (Smith et al. 2009).

With reference to this study, Husserl's work, as interpreted through IPA, provides a conceptual argument for the exploration of personal experience as a means of developing knowledge and understanding of a particular phenomenon. The phenomenon of interest for this study is cerebellar ataxia as understood from the perspective of people who live with this condition. As such, an exploration of ataxia as a phenomenon of human experience, undertaken with respect to Husserl's orientation

towards the careful examination of experience in the way that it occurs, retains the Husserlian perspective of IPA and should help to shed light on and develop knowledge about this phenomenon.

#### **4.3.1.2 Heideggerian Phenomenology**

Heidegger (1889-1976) changed the direction of phenomenology with his most famous work, 'Being and Time' (1962 [1927]). This work signalled a move away from Husserl's interest in consciousness towards the question of being. Heidegger was interested in the meaning of being, what it is to be human; the fundamental nature of human being or human existence (Moran, 2000; Gerner, 2007).

Heidegger's view was that humans are already thrown into, or caught up in, a world full of things, culture, people and language and cannot be meaningfully separated from this context or choose to opt out to see things from a different perspective (Moran, 2000; Larkin et al. 2006). For Heidegger, human being is 'Dasein' (Heidegger, 1962 [1927]:8), translated as there-being or human-being-in-a-situation (Becker, 1992; Moran, 2000). The running together of the words here stresses the connectedness of human, being and world. Critically, and of significance to IPA and its aim to understand people and their experiences, Heidegger proposed that existence is not a thing out there in the world, some "thing" called existence in a general sense, rather, it is always somebody's existence, personal and owned (Becker, 1992; Moran, 2000). Heidegger's term 'facticity' expresses this fundamental situatedness of human being, described by Moran (2000:223) as 'the particular, concrete, inescapably contingent, yet worldly involved aspect of human existence'. Phenomenological enquiry faithful to Heidegger's ideas, such as IPA, should therefore carefully take account of particular people and the particular contexts and situations with which they are engaged (Becker, 1992; Smith et al. 2009).

Facticity also speaks to IPA more specifically than simply in terms of understanding that individuals are individuals-in-context. According to Heidegger, individuals have choices, i.e. they can respond to their facticity in a number of ways, although the range of options is not unlimited (Heidegger, 1962 [1927]:13). What seems critical is that Dasein has these possibilities; it makes decisions, and chooses its way of being (Inwood, 2000; Gerner, 2007). Dasein's being therefore, unlike other entities in the world, 'is an issue' for it (Heidegger, 1962 [1927]:181); it has concerns, it questions its existence, worries about its decisions and wonders what to do next (Inwood, 2000; Moran, 2000). Heidegger (1962 [1927]:183) calls this basic condition of Dasein 'care'. This is a

collective term that speaks for Dasein's insertion in the world (thrownness), its interrelatedness (concern), as well as its temporality; always projecting into the future (thinking about what to do next) with respect to the past (Inwood, 2000; Gerner, 2007).

Taking account of Heidegger's concept of care and the worldliness of Dasein, IPA should therefore be oriented towards understanding the particular cares and concerns of an individual. Researchers should try to attend to the things and the people that individuals are actively engaged with (events, worries, the things they dwell on) and how these colour their particular situation in the world and the meaning it holds, in other words how these orientations help to reveal their particular being-in-the-world (Larkin et al. 2006; Smith et al. 2009). This is not a straightforward process; it asks the researcher to find out about someone through understanding the context of their life (Larkin et al. 2006) and therefore connects Heidegger's phenomenology to its hermeneutic orientation (discussed below with reference to the interpretative stance of IPA). The relevance for this study is that the researcher should allow participants to dwell upon the things that are important to them, the things they care about, rather than trying to lead them in a pre-determined direction that may hold little meaning for the individuals themselves. For example, with reference to the present study, the researcher had to re-examine encultured interests and assumptions established through her profession as a physiotherapist in order to connect with and understand the particular concerns and perspectives of the participants.

#### **4.3.1.3 Merleau-Ponty's Phenomenology**

The French psychologist and philosopher Maurice Merleau-Ponty (1908-1961) aligned himself with Husserl's rather than Heidegger's phenomenology but like Heidegger, he extended the Husserlian perspective to include a contextualised and situated phenomenology which also reinterpreted Husserl's conception of the living body (Moran, 2000; Carman, 2008). Merleau-Ponty emphasised human embodiment as central to human experience, and the complex intertwining of body, self and world as the way in which human beings encounter and understand the world (Moran, 2000; Carman, 2008; Morris, 2008a).

For Merleau-Ponty, body and world (material and social) are integrated and embedded; 'Our own body is in the world as the heart is in the organism' (Merleau-Ponty, 2002 [1945]:235). This means that human existence or the human condition cannot be understood or experienced as if from the outside, as if human experience is in some sense bodiless and detached (Carman, 2008): 'there is no inner man, man is in the

world and only in the world does he know himself' (Merleau-Ponty, 2002 [1945]:xii). Heidegger argued that being in the world is always understood as *somebody's* being in the world (Matthews, 2006). However, Merleau-Ponty emphasised that it is always somebody's *embodied* being in the world because for him 'The body is the vehicle of being in the world' (2002 [1945]:94). It is this contact and communication with the world, through one's *own* body, which results in there being a world of meaning (Matthews, 2006). This is because, according to Merleau-Ponty, the world is 'lived' through the body; 'The world is not what I think, but what I live through' (2002 [1945]: xviii). The world is understood in the first instance through the body and because of this it is already meaningful before it is thought about and reflected upon (Reynolds, 2005; Morris, 2008a).

Research undertaken with respect to Merleau-Ponty's phenomenology, understands the world not as some abstract concept, something that is merely thought about, but as something that is wholly and bodily experienced (Matthews, 2006). Merleau-Ponty's work seems to suggest that any change to the way in which the body interacts with and encounters the world would alter the way in which that person makes sense of themselves and their world (Morris, 2008a; Rothfield, 2008). Therefore, without pre-judging, it might be important in the present study to attend to the ways in which the participants speak about their bodily experiences of ataxia, how they make sense of these experiences and what this may reveal about their being in the world.

#### **4.3.1.4 Sartre's Phenomenology**

Jean-Paul Sartre's (1905-1980) publication of 'Being and Nothingness' (2003 [1943]) developed the existential orientation of phenomenology as originally put forward by Heidegger (Moran, 2000). For Sartre, human nature is not fixed; it is about becoming, coming into being, away from the past, and always projecting towards the future (Cox, 2008). In this sense, the self is always being formed or reshaped, it is not an entity to be discovered fully fledged but is always in the making. Because human existence is not about being as an established thing but about becoming, people face choices about their lives and what they want to become (Cox, 2008). In Sartre's words, human beings 'are condemned to be free' (2003 [1943]:462). This freedom to make choices about one's life carries responsibility and operates in relation to a person's individual, social and cultural situation (Moran, 2000). For Sartre, there is both 'freedom and facticity' (Manser, 1966:129). To phrase it differently, human engagement in the world is personally situated and inevitably attended by relations with others who are also in the

world and who also have their own projects which challenge and shape the experience of other individuals. This stress on human existence as being qualified by other people and social relationships remains one of Sartre's main contributions to phenomenology (Smith et al. 2009).

Sartre's work therefore speaks to IPA by emphasising how a particular phenomenon might influence a person's projects and relationships with others and their sense of existential freedom, their sense of being a person-in-the-making. Researchers who are attentive to the projects and people that concern individuals, and their responses to the choices they face, might therefore be in a position to illuminate relevant and meaningful aspects of their participants' being-in-the-world that might otherwise remain hidden. In the present study therefore, it might be important to pay attention to the way in which participants talk about their encounters with others such as physiotherapists and the impact this may have on their lives.

In summary, IPA is connected to the core principles of phenomenology through paying respectful attention to a person's direct experience. Individuals are encouraged to dwell upon a significant, concrete experience whilst researchers are encouraged to be open to the claims and concerns identified by each participant. IPA researchers also articulate phenomenological concepts through their understanding that experience is not only individually embodied, situated, and based on personal biographies, but is context dependent and contingent upon relationships with others, coloured and shaped by society and culture (Eatough and Smith, 2008; Smith et al. 2009). IPA does not reveal an inner experience. What becomes known is only possible by understanding the person-in-context, the things that matter to them in the world (Larkin et al. 2006). The researcher's role is to try to make sense of this complex data, to uncover meaning, whilst avoiding over-hasty recourse to generalisations and reference to a priori concepts, categories or theories. This is a complex process which for IPA involves phenomenological description but also interpretation. The interpretative stance of IPA is discussed next.

#### **4.3.2 Interpretation (Hermeneutics)**

Hermeneutics is defined as the theory and practice of the interpretation of the meaning of texts (Rennie, 1999). The interpretative orientation of IPA draws on the theoretical perspectives of three hermeneutic theorists; Heidegger, Schleiermacher and Gadamer (Larkin et al. 2006; Smith, 2007; Smith et al. 2009). The intention here is not to produce

a potted biography of these philosophers but to demonstrate the relevance of their work to IPA and in particular to this study.

Schleiermacher (1768-1834) was a theologian and philosopher concerned with the interpretation of religious texts (Bowie, 1998). He proposed that a detailed and thorough interpretation of a text, directed towards both a linguistic analysis (looking underneath years of incremental accretion to reveal the original meaning of the script), as well as a psychological analysis (looking at what was said and how it was said), would reveal the meaning of the text whilst at the same time revealing something of the (un)intentional motivations of the original author, that is meaning *beyond* the immediate claims of the individual (Moran, 2000; Smith et al. 2009). The psychological analysis which seems to have a clear resonance with IPA was founded upon two interconnected methods: firstly, the 'divinatory' method where the analyst 'transforms oneself into the other person, and tries to understand the individual element directly' and secondly, the comparative method where the analyst understands 'the person to be understood as something universal and then finds the individual aspect by comparison with other things included in the same universal.' Both methods are interrelated; the first method depends on 'the fact that every person, besides being an individual themselves, has a receptivity for all other people' which also rests on understanding that 'everyone carries a minimum of everyone else within themselves, and divination is consequently excited by comparison with oneself' (Schleiermacher, 1998 [1810]:92-93).

IPA's reading of Schleiermacher suggests researchers cannot claim to know another person through pure intuition (e.g. through contemplation from a distance) but that it is possible to get psychologically close to another's lived experience by empathically trying to stand in their shoes (the divinatory method) and by identifying similarities with themselves, but by also looking for differences (the comparative method), (Smith et al. 2009). What Schleiermacher described as 'receptivity' (1998 [1810]:93) provides the starting off point for understanding the experience of another. Put in other words, human beings have a pre-reflective, practical or common sense understanding of what it is to be human which provides the context and foundation for gaining access to the meaning of another person's experience (Packer, 1985).

The interpretative process is not straight forward, it is dynamic, and as initially discussed in chapter 1, what emerges (in research terms) is a co-construction built by the ebb and flow between the participant and the researcher. A dual interpretation takes place; the participant makes sense of a phenomenon in their own terms by explaining and

interpreting their own experience, and further elaborations may be offered in response to further questions. Smith and Osborn (2003:51) used the term 'double hermeneutic' to emphasise the two interpretations involved; the first is the participant's meaning-making (interpreting their own experience), the second is the researcher's sense-making (interpreting the participant's account), (Smith et al. 2009). The circularity of the process (questioning, uncovering meaning, and further questioning), involved in interpreting and understanding a phenomenon is the hermeneutic circle (Moran, 2000; Smith, 2007; Smith et al. 2009). The journey round the hermeneutic circle is driven by evolving hermeneutic questions. The final analysed account should offer a layered analysis of the phenomenon; firstly a descriptive, phenomenological level which conveys an empathic understanding of the experience, the emic position, and secondly a probing, more critical analysis based on the deeper interpretative work of the researcher, the etic position, which seeks to make sense of the participant's account (Smith, 2004; Reid et al. 2005; Eatough and Smith, 2008; Larkin et al. 2006; Smith et al. 2009).

For Schleiermacher interpretation was an 'infinite task' (Bowie, 1998: xxx), perhaps best explained in the following extract:

"the image of the whole becomes more complete via the understanding of the particular and the particular is more and more completely understood the more one gets an overall view of the whole" (Schleiermacher, 1998 [1810]:232).

Schleiermacher's position in terms of bringing together the whole (understanding the context of a text) as well as the part (understanding the author) has a contemporary resonance for IPA (Smith, 2007; Smith et al. 2009). Data analysis proceeds in a somewhat linear fashion but it is also necessarily circular and iterative, recognising that 'one must continually slip back to what came earlier' (Schleiermacher, 1998 [1810]:232). Within the hermeneutic circle researchers revisit the parts or instances that make up the whole and revisit the whole or the overview to understand the part. This part-whole analytic process occurs at multiple levels, from the level of a word to a sentence, up to the level of a single account, to the complete corpus (Smith, 2007; Smith et al. 2009).

The double layered hermeneutic analysis resonates with the classical hermeneutics of Schleiermacher but it is applied within a postmodern context. As noted by Smith (2007), Schleiermacher interpreted public documents, which were written at an historical distance from and therefore in the absence of the interpreter. Hermeneutics as applied to IPA is concerned with personal texts that are co-constructed by the research

participant and the researcher, in the present-day, and usually face to face. Meaning therefore unfolds during the construction as well as during the analysis of these “texts”. The analysis in this respect is not timeless, it is embedded in the participant’s and the researcher’s current position (Larkin et al. 2006).

Building upon Schleiermacher’s theories of interpretation, Heidegger fused his understanding of phenomenology with the theories of hermeneutics. Heidegger’s position was that human existence is utterly and indissolubly bound up in the world, a world of people, things, language, relationships and culture. Therefore it is impossible for anyone (researcher or participant for example) to *opt* to transcend or disconnect from these indelible facets of their lives in order to reveal some fundamental truth about lived experience or the nature of being (Larkin et al. 2006). In this respect, all enquiry starts from the enquirer’s perspective, from the basis of their experience.

Heidegger (1962 [1927]:150) explained that interpretation is grounded in prior experience (*fore-having*). The process of interpretation unveils, cuts into or exposes something the interpreter was already partially aware of (*fore-sight*). Whatever is held in our fore-having and revealed through fore-sight is assigned meaning on the basis that it was already anticipated or grasped in advance, in a *fore-conception*. Therefore, for Heidegger, there is no presuppositionless starting point because whenever something is interpreted as something it is grounded upon fore-having, fore-sight and fore-conception; it is always in some way ‘fore-given’ (Macquarrie and Robinson, 1962:192). Put another way, researchers, in this sense, cannot interpret another person’s experience of a phenomenon without bringing in something of themselves, without drawing on their own resources (Packer, 2011).

Rather than setting aside or bracketing preconceptions and assumptions in advance of an enquiry, IPA researchers work from a Heideggerian perspective by *trying* to identify their basic understandings of a particular phenomenon but acknowledge that an awareness of these fore-conceptions may not come to light until work has started in the interview or the analysis, i.e. until the phenomenon has started to emerge (Smith et al. 2009). IPA researchers are therefore urged to adopt a ‘sensitive and responsive’ approach to data collection and analysis that allows the researcher’s preconceptions to be prodded and adjusted by the data (Larkin et al. 2006:108). Careful attention to the cares and concerns of the participant creates a dynamic or cyclical form of bracketing (somewhat akin to the more familiar processes involved in reflective practice) which occurs *as part of* the research process (Smith et al. 2009). In this respect, whilst it may be *possible* to bracket scientific and theoretical assumptions about the topic of interest,

even these assumptions may only emerge to consciousness once a researcher has started to engage with the data.

IPA researchers therefore understand that all questioning and interpretation carries assumptions based on prior experience that govern the extent of what can be disclosed. Consequently the phenomenon can never disclose itself in its entirety and interpretative work is required to understand the meaning of the (partial) disclosure (Packer, 1985; Moran, 2000). For IPA researchers this means that what is captured of another's experience using IPA will always be indicative and provisional rather than absolute and definitive because the researchers themselves, however hard they try, cannot completely escape the contextual basis of their own experience, and neither can they completely immerse themselves in the life of another person (Larkin et al. 2006). Ultimately a rich and nuanced understanding of the phenomenon should be revealed, based on interpretative effort but a perfect understanding of the essence of the experience will always remain hidden.

Gadamer (1900-2002) made a significant contribution to the contemporary understanding of hermeneutics with his major work, *Truth and Method* (1960). Gadamer's perspectives were aligned with those of Heidegger and re-emphasised the lived experience of the interpreter as both a way into the text as well as a hindrance to understanding:

“A person who is trying to understand is exposed to distraction from fore-meanings that are not borne out by the things themselves. Working out appropriate projections, anticipatory in nature, to be confirmed ‘by the things’ themselves, is the constant task of understanding’ (Gadamer, 2004 [1960]:270).

The interpreter's fore-meanings may be identified in advance or may only emerge through the process of interpretation. As meaning emerges through interpretative effort, these fore-meanings or prejudices are adjusted prompting new questions to be asked of the text which ‘open up possibilities of meaning’ and in turn new meanings may emerge (Gadamer, 2004 [1960]:368). For Gadamer, prejudices, based on historical and sociocultural traditions, form part of the structure of human experience and cannot be simply shaken off in an attempt to arrive at a presuppositionless starting point. Instead, prejudices are the jumping off point where, through engaging in dialogue, pre-judgements emerge and the process of understanding gets underway (Moran, 2000).

For IPA researchers, Gadamer's view, as outlined here, not only describes what might happen during the analytic process i.e. how the analytic process might work itself out (Smith et al. 2009) but it also affirms the potential value of identifying and working with pre-understandings. For example, through working with a participant's data a physiotherapist-researcher may need to question a common sense but naïve view that walking aids promote well-being for a person with ataxia because they are designed to reduce impairment and promote safe ambulation. Gadamer (2004 [1960]:304) might describe this questioning process as the testing of prejudices in the search for 'a superior breadth of vision' that overcomes the researcher's own particularity. However, Gadamer also recognises that it is impossible to see everything. The visible horizon (what can be seen) is realised from a particular vantage point defined, at least at first, by the prejudices carried by the interpreter (Packer, 2011).

In summary, IPA declares its interpretivist stance by claiming affinity with the hermeneutic traditions articulated by Schleiermacher, Heidegger and Gadamer. IPA acknowledges that gaining access to another person's lived experience is possible but not straight forward and never fully realised. The final account is a construction built by the researcher and participant(s). The authenticity of this, at least in part, relies upon the researcher's effort, skill and determination to reflexively learn from the data. The extent to which this can be accomplished and how it can be evaluated is discussed in more depth in the following methods chapter.

#### **4.3.3 Idiographic Inquiry**

As with much qualitative research IPA is committed to an idiographic approach. Idiography is concerned with the particular, the distinct experiences of particular people and the particular contexts in which those experiences occur (Smith et al. 1995; Eatough and Smith, 2008; Smith et al. 2009). Working from an idiographic stance means that individuals should be understood '*in-relation-to* phenomenon' and not as isolated entities in and of themselves (Smith et al. 2009:29, emphasis in the original); put another way, the aim should be to understand the particular 'in the fullness of whatever contexts are relevant' (Sandelowski, 1996:526).

Consistent with the idiographic approach, small samples are commonly advocated (Smith and Osborn, 2008; Smith et al. 2009). This approach is not only practical in terms of the analytic work involved but also enables the detail and the depth of each experiential account to be made as visible as possible to the reader. The case is central

to the inquiry; the researcher attempts to understand each person as a unique being-in-the-world whose cares and concerns are never going to be precisely the same as any one else's (Allport, 1962). Therefore findings from each case are set aside (as far as possible), through a dynamic form of bracketing within the hermeneutic circle, in order to maintain sensitivity to each person's distinct story (Smith et al. 2009). During the final cross-case analysis the researcher attempts to remain faithful to individual accounts through illustrating the particular lifeworld of participants who have recounted their experiences whilst also illustrating more general themes (Smith and Eatough, 2006). In this way a picture is built up of the general as well as the particular experiences of individuals (Smith and Osborn, 2008). This facility for highlighting unique perspectives as well as shared experiences is one of the cornerstones of IPA (Smith, 2004, Smith and Osborn, 2008).

#### **4.4 The Ethical Dimension of Phenomenological Hermeneutics**

Smith et al (2009:37) summarised the co-dependency of hermeneutics and phenomenology as articulated in IPA as follows; 'Without the phenomenology, there would be nothing to interpret, without the hermeneutics, the phenomenon would not be seen.' IPA researchers do not attempt to produce an objective or definitive account of a phenomenon and only claim to access a version of the experience as the participant makes sense of it through their narrative account (Smith and Osborn, 2008). Researchers would never claim to fully understand another person because there will always be a difference in thinking, a gap, between the speaker and the listener which can never be fully resolved (Schleiermacher, 1998 [1810]). Packer (1985:1089) has perhaps best articulated the limits of the extent to which researchers are capable of fully grasping the experience of another:

'understanding is not seen as a "searchlight" that scans over a field of potential knowledge but rather as a kind of appreciation that is necessarily partial (in both senses of the word: incomplete and with its own point of view).'

Layers of resistance are met by the researcher in analysing the narrative; hidden meanings, metaphorical references, linguistic signals. Particular temporal circumstances also influence what is glimpsed and understood (Smith, 2007). At the same time, the researcher's own resources and experiences, what Smith (2004:45) refers to as the 'biographical presence' of the researcher, are needed to make sense of what is said and yet this biography also provides another layer of resistance. This creates a dynamic

tension throughout the research process. In order to work this out, researchers make use of their own contexts as sources of insight whilst being (or trying to be) explicit about the influence of their perspectives on the analysis and interpretation of the narrative (Finlay, 2008). However, the researcher's preconceptions may not be clear at first and only come to light through further engagement with the text and a willingness to reflect (Smith et al. 2009).

The hermeneutic circle is therefore a powerful means of engaging with the things of experience but it may require considerable interpretative effort. Packer (1985:1091) described 'returning to the object of inquiry again and again, each time with an increased understanding and a more complete interpretative account'. This effort not only refers to the commitment to the iterative process but also the need for an on-going reflexive awareness of the interpreter's position in relation to the data. Researchers' decisions about what constitutes the "best" hermeneutic questions and the most appropriate analysis carry implications. Tappan (1997) advised researchers to be mindful of the ethical dimension of this interpretative work and the inherent power that comes with the possibility of shaping and distorting the perception of another's lived experience. It is not simply a case of telling another person's story or of allowing the "things" to show themselves as themselves because, as discussed previously, by attempting to understand the meaning of a text the researcher's own values, biases and assumptions come into play. Tappan (1997) urges researchers to be attentive to the inherent power in defining the "right" interpretation, so as not to unintentionally disrespect participants who hope their lives will be understood. Packer (1985:1092) suggested that hermeneutic analysis should aim to be 'subtle and complex, intellectually satisfying' (for the reader and the researcher), whilst embracing ambiguity and opacity. This seems to be an appropriate aspiration for the sort of work entailed by the present study and cautions against the production of an uncluttered perhaps artificially neat analysis that does not do justice to the participants' lifeworlds.

#### **4.5 Clarification of the Epistemological and Ontological Perspective of IPA**

The present study is connected to IPA's fundamental theoretical perspectives because it seeks to develop knowledge inductively on the basis of empathically understanding the experiences of people-in-context (the epistemological and phenomenological stance) and, via a more questioning hermeneutic, it expects the data to reveal multiple perspectives which are not independent of the researcher (ontological and interpretivist stance).

Similar in some ways to the development of grounded theory (Pawluch and Neiterman, 2010), IPA as a relatively new approach to qualitative research continues to expound its theoretical position and to clarify where it stands with reference to other approaches to qualitative inquiry. Whilst prioritising the phenomenological and interpretivist stance of IPA, several authors have clarified the relationship between these and the fundamental ontological assumptions underpinning IPA (Smith, 1996; Reid et al. 2005; Larkin et al. 2006; Smith and Osborn, 2008; Eatough and Smith, 2008; Smith et al. 2009). What these accounts share, in terms of ontology, is a declaration of IPA's affinity with symbolic interactionism or soft social constructionism, which consistently places IPA somewhere in the middle ground between realism and relativism. Of these authors, Larkin et al (2006) perhaps offered the deepest consideration of both the epistemological and ontological stance of IPA and how these positions contribute to a considered understanding of phenomenology and hermeneutics.

Larkin et al (2006) used the term 'contextualist' to describe and unite IPA's epistemological and ontological position. Contextualism is characterised by a commitment to 'exploring, describing, interpreting and situating the means by which our participants make sense of their experiences' (Larkin et al. 2006:110). This conceptualisation best captures the epistemological orientation of IPA which is concerned with developing knowledge and understanding people-in-context but it does not fully address the ontological position.

Larkin et al (2006:110) specifically described the ontological stance of IPA as 'minimal hermeneutic realism' with reference to Dreyfus' interpretation of Heidegger's understanding of reality (Dreyfus, 1995:254). IPA's commitment to Heidegger, and Heidegger's position as a hermeneutic phenomenologist, suggests that his work may well provide the best steer for understanding the ontological position of IPA. Larkin et al (2006) explained that Heidegger was a *realist* in that he accepted that things exist, that these things are real and would exist even if humans did not. This realism is minimal because the question about the independent existence of things only occurs because people exist and ask the question. Heidegger's position with respect to reality was *interpretivist* because meaning does not belong to the object. As Dahlberg et al. (2008) suggested, meaning is not something with independent existence that can simply be happened upon; meaning is made in the encounter. Put another way, the things of experience are real but the meaning of a particular thing (e.g. this desk, this illness) is not transparent or invariable. People make sense of things through their engagement with them and as 'sense-making creatures' they impose meaning on their experiences

which is perspectival or individually situated (Smith et al. 2009). This means that if objective reality is understood as being constituted through intellectual or subjective sense-making then what a participant recounts in an interview reveals something very real about the phenomenon of interest (Larkin et al. 2006). IPA recognises the complex relationship between what people think, what they say and what they do, but assumes that the participant's account is at least in part a reflection of what they think about the topic of interest (Smith, 2007; Eatough and Smith 2008). IPA therefore holds that an individual's account reflects something of their subjective experience, and provides a genuine portal to their experiential world, however, this position does not suggest that access to this world of experience is unproblematic.

In comparison to IPA, interviews conducted for discourse analysis (a method of inquiry similar to IPA but with stronger social constructivist claims) are not taken as a means of accessing people's psychological and social worlds (Coyle, 2006). Rather than focussing on an individual's involvement in a particular context, discourse analysts focus on understanding the structure of the context and how linguistic resources have been used to construct a version of events (Marshall, 1994; Coyle, 2006; Smith et al. 2009). So whilst IPA may share an interest with discourse analysis in understanding how experience is immersed in context, IPA's concern lies at the level of the individual and their personal involvement in the context whereas discourse analysts' interest lies in the language (Smith et al. 2009; Kelly, 2010). IPA's orientation fits more closely to the aims of the present study and its interest in learning about the individual experience of people living with ataxia. Its stance towards developing an in-depth, fine grained understanding of the lives of a few individuals with ataxia also takes the present study away from the more macro-level analysis as conceptualised via grounded theory (Glaser and Strauss, 1967; Pawluch and Neiterman, 2010).

The ontological and epistemological position described above is consistent with the researcher's personal affinity with Engel's (1977) biopsychosocial model of clinical practice. Using this model, clinicians pay attention to the reality of a person's symptoms but also considers it essential to effective healthcare to understand a person's subjective experiences and to situate the condition within their personal and social world (Borrell-Carrió et al. 2004). This position seems to share common ground with the lifeworld perspective of human science research as articulated by Dahlberg et al (2008) and connects with the fundamental orientation of IPA (Reid et al. 2005).

#### **4.6 A Comparison of IPA with Other Forms of Phenomenological Inquiry**

The difference between affiliated but separate approaches towards phenomenological inquiry has been described by Smith et al (2009:200) as a little 'fuzzy'. With the intention of positioning this study clearly within the IPA stable of phenomenological enquiry, and without intending to diminish the value of other work, this next section briefly explicates the present study's position with respect to four other significant phenomenological approaches, Giorgi's descriptive phenomenology (1995), Ashworth's descriptive phenomenology (2003); Dahlberg et al's (2008) reflective lifeworld research and van Manen's (1990) hermeneutic phenomenology.

Giorgi's (1995) descriptive phenomenology claims a Husserlian orientation and through this an emphasis on consciousness. It is aligned with other descriptive phenomenologies such as those outlined by Moustakas (1994) and, like this approach it is primarily concerned with developing a general description of the structure of the phenomenon, for example the invariant or essential constituents of the process of learning to drive (Giorgi, 1995). In contrast, the present study is not primarily concerned with understanding the invariant features of the lived experience of progressive cerebellar ataxia. Trying to uncover its invariant features seems a little premature without firstly getting a sense of the texture and the detail of the cares and concerns that particularise individuals' lives. An idiographic approach allows the research to go deeply into an individual's world, engaging with the 'messy and chaotic' aspects of life (Eatough and Smith, 2008:183) in the hope of bringing out the texture and nuance that leads to a more informed understanding of the phenomenon under investigation. The present study will undoubtedly uncover commonalities but in keeping with IPA's core principles it will intentionally seek divergence as well as convergence and will retain IPA's commitment to understanding individual experience first and foremost and will only cautiously make more general claims.

Ashworth's descriptive phenomenology (2003), also known as the Sheffield School, is aligned with Giorgi's descriptive phenomenology (Langdrige, 2007). Ashworth's stance is strongly idiographic and unlike much descriptive phenomenology it does not attempt to identify the invariant features of the phenomenon but to reveal differences as well as some sense of the commonalities, should these emerge during data analysis (Ashworth, 2003). The Sheffield School also differs from other forms of descriptive phenomenology by using seven 'fractions of the lifeworld' to interrogate the data (selfhood, sociality, embodiment, temporality, spatiality, project and discourse), (Ashworth, 2003:147). These fractions are broadly based on the work of the phenomenological philosophers

discussed earlier in this chapter but with a strong emphasis on Merleau-Ponty. Ashworth (2003) described a fluid, heuristic analytic process in which some of the fractions may be more resonant than others in a particular analysis and where researchers are free to use only some fractions if others are deemed irrelevant. However, this particular approach to phenomenological enquiry was not chosen for the present study because the aim of this study is to focus on and be fully open to the experiential perspectives of the participants themselves. Attempting to fit their lifeworld concerns to pre-defined and academically constructed categories, however loosely and retrospectively applied, would seem to threaten the prioritisation of the participants' perspectives as framed within the research question and as articulated with reference to the researcher's grounding in the biopsychosocial model of clinical practice.

Reflective lifeworld research (Dahlberg et al. 2008) seems to be closely aligned to the philosophical orientations of IPA. Like IPA, it claims phenomenological and hermeneutic roots and identifies Husserl, Heidegger, Merleau-Ponty and Gadamer as key influences. However, whilst retaining a hermeneutic orientation, reflective lifeworld research combines a Husserlian search for essences with a particular form of bracketing called 'bridling' (Dahlberg et al 2008:129). This form of bracketing works to restrain understanding by slowing down the evolving interpretation as it emerges in front of the researcher to allow the phenomenon to show itself as far as possible as itself, before it is tied down to a specific interpretation (Dahlberg et al. 2008). Finlay (2011:128) has argued that this particular phenomenological approach has, in recent years, become closely affiliated with a humanising philosophy called 'lifeworld-led care'. This emphasis was not evident at the start of the present study in 2006 and therefore its possible relevance as an appropriate methodology for understanding the lived experience of progressive cerebellar ataxia could not be anticipated.

Finally, van Manen's (1990) hermeneutic phenomenology is also closely aligned to IPA (Langdrige, 2007; Smith et al. 2009) and, on first reading, it is difficult to see what separates these two approaches. van Manen's primary interest in the experience of practice (health care and teaching), and his deeper consideration of Gadamer's interest in language suggest quite nuanced differences (Langdrige, 2007). However, and perhaps more critical to the present study, Langdrige (2007) highlights van Manen's (1990) flexible approach to data collection which permits the researcher to contribute his/her own perspectives to the encounter as well as to approach analysis using similar structures of the lifeworld described by Ashworth (2003). The intentional contribution of the interviewer's own views during data collection, rather than working out fore-

conceptions as part of the hermeneutic process, would seem to run counter to the intentions of the present study. IPA's commitment to 'allowing participants to tell their own story, in their own words' (Smith et al. 1997:68) seems to fit the aims of the present study more closely. Furthermore hermeneutic phenomenologists skilfully exploit literary, philosophical, theoretical and reflexive perspectives, taking phenomenology into the realms of poetic or aesthetic forms (Finlay, 2011). Good IPA is similarly deeply interpretative (Smith et al. 2009) but it does not seem to make the same claims for literary, metaphorical and artistic expression. For these reasons hermeneutic phenomenology was not adopted for this study.

#### **4.7 Summary**

This chapter presented IPA as an appropriate means of addressing the research questions articulated in the present study. Its theoretical position was explored in depth and the epistemological and ontological basis of enquiry was discussed and clarified. The decision to select IPA instead of alternative and related methods of phenomenological inquiry was justified. Two important issues were raised in this chapter for the first time; ethical considerations and the grounds on which a judgement might be made about the quality of analysis and reported findings. These issues are explored in more depth in the following chapter which details and discusses the methods involved in using IPA to answer the research questions.

## **Chapter 5**

### **Method**

#### **5.1 Introduction**

This chapter details and justifies the methods employed in this study and discusses pertinent ethical issues and the ways in which quality and rigour have been addressed.

#### **5.2 Research Questions**

This study aimed to conduct an in-depth exploration of the lived experience of progressive cerebellar ataxia. The enquiry focussed on understanding how people living with progressive cerebellar ataxia made sense of their condition in the context of their everyday lives and how they perceived exercise, physiotherapy and physiotherapy services. By using an inductive approach which prioritised the perspectives of the participants' experiences, via in-depth interviews, it was hoped that the subjective meaning of progressive cerebellar ataxia could be interrogated and elucidated. This study employed IPA (Smith et al. 2009) to explore the following research questions:

1. What is the meaning of progressive cerebellar ataxia for people who live with this condition?
2. How do people living with a progressive cerebellar ataxia experience healthcare, and physiotherapy in particular?
3. What is the meaning of exercise and activity participation for people living with progressive cerebellar ataxia?

#### **5.3 Research Ethics Considerations**

NHS approval was not required for this study because participants were not drawn from NHS sources (<http://www.nres.nhs.uk/applications/approval-requirements/>). This study was approved by the School of Health Sciences and Social Care Research Ethics Committee, Brunel University (Appendix Ca). Only minor revisions were required to the original application for approval.

Research ethics approval was originally given for conducting focus groups with people living with ataxia and, separately, with physiotherapists working with people living with ataxia. This second part of the approved study (qualitative work with physiotherapists) is not part of the work presented in this thesis. It is noted here for clarity, as it is mentioned in the participant information sheet (Appendix D). As part of the recruitment process, potential participants were informed of the aims and purpose of the study (via the

participant information sheet) and, via e-mail or telephone, opportunities were provided to ask questions. During recruitment, although interest in the study was high, it emerged that potential participants were located in all areas of the UK, and as such it proved impossible to convene focus groups as originally planned. This issue was discussed with potential participants who informally suggested that they would still be interested in the study if in-depth interviews were used instead of focus groups. An amendment request was therefore submitted to the Research Ethics Committee to conduct in-depth interviews instead of focus groups. The consent form was altered to reflect the change in data collection method (Appendix E). The amendments were approved (Appendix Cb), and the recruitment process continued as described in section 5.4.

Following recruitment, as part of the introductory conversation before the interview, the aims of the study were reiterated, the broad scope of the interview outlined, anonymity and voluntary participation confirmed, right to withdraw without detriment established, further questions answered and consent forms signed. Ataxia UK leaflets were taken to all interviews as a source of further information and support. As the differences between spoken and written language and the potential for offending participants through sending them raw data are well recognised (Kvale and Brinkmann, 2009) individual transcripts and the final narrative accounts were not circulated to the participants in this study. However, as part of the research ethics approval, summaries of the main findings which contained some anonymised direct quotations were circulated to all participants. The summarised findings were well received and did not raise any concerns. The following discussion briefly contextualises and discusses a few of the particular ethical issues inherent in the present study.

The aim of this study, to understand the meaning of living with ataxia, was a serious undertaking; participants were asked to reflect on an enduring, uncertain and intensely personal lived experience. Attending to the potential ethical issues inherent in procuring and reporting these experiences required an understanding of ethical responsibilities which transcended the procedures formally embedded in research ethics approval processes. In other words, research ethics approval did not mean that ethical dilemmas had been “fixed”, rather that problem areas had been flagged for on-going consideration (Kvale and Brinkmann, 2009).

Kvale and Brinkmann (2009:61) argued that proper ethical conduct is dependent upon the Aristotelian concept of practical wisdom or phronesis, ‘the intellectual virtue of recognising and responding to what is most important in a situation’. This does not mean that ethical principles are abandoned rather that ethical salience is situation-specific i.e.

the point at which an issue becomes morally relevant is determined by context not through recourse to universal principles or rules. Principles based guidance provides a framework for ethical research conduct but only helps the researcher anticipate problems in a general sense. Much therefore depends on the researcher's ability to judge interacting moral, ethical and epistemic dilemmas which emerge through concrete human interaction (e.g. in the interview situation).

Through reflexive activity which focused on understanding situated ethical dilemmas, reasoning processes and actions, this researcher learned better ways of recognising and responding to ethical issues apparent in the present study. For example, as the researcher was a physiotherapist it was possible that potential participants might believe the study would offer some form of therapeutic intervention; a particular problem in health research (Stark and Hedgecoe, 2010). The Participant Information Sheet and subsequent conversations with participants stressed that interventions would not be offered as part of this study, nevertheless this did not stop participants asking for advice and reassurance not only about physiotherapy but also about medical and other personal issues. The researcher directed participants to other sources of support for concerns outside her area of expertise. However, it felt morally and professionally wrong to withhold information that could potentially reduce anxiety and distress. An example of the sort of ethical dilemma which arose in the present study is provided in Box 5.1 (pp. 86).

The view that qualitative research is in some way inherently ethical because it seeks to understand human experience and action in an empathetic and meaningful way has been refuted in the literature (see for example Punch, 1998; Brinkmann and Kvale, 2005). Seeking to provide vulnerable people with a voice in research is complicated not simply by issues of consent and autonomy but also by undeclared "qualifiers" such as 'narrative competence' (Kirkevold and Bergland, 2007:71). As discussed in chapter 2 (Understanding the Subjective Experience of Long Term Illness) although participants were not asked to "tell their story", there was an unacknowledged expectation in this study that participants would be able to talk about and reflect upon their experiences in a detailed and coherent fashion. Although the majority of participants in the present study needed little help in providing in-depth narratives about what life was like with ataxia, one or two struggled. Julia, for example, asked the researcher to '*ask me questions*' to prompt her and to help continue her narrative. Joan required some reassurance that her contribution was valid and valued; she asked '*Is that a good enough answer?*' In this situation the researcher worked within the interview to support participants to find their

voice, by reassuring them that their views were important and by using their words to help develop avenues for further discussion.

### **Box 5.1: Research Ethics Vignette**

One participant (Stella) asked the researcher to make sense of a letter that had been written by her consultant and sent to her as part of the practice of copying patients in to all correspondence. This letter was not written in lay language and the participant was frustrated and anxious about not understanding what had been written about her and her particular problems. Whilst suggesting that the participant might perhaps ask her GP for help, the researcher did explain most of the contents of the letter in a way that Stella could understand.

Stella made the request in the latter stages of the interview. It could be suggested that during the time that had elapsed since meeting the researcher for the first time and tentatively introducing the letter, Stella had decided to trust the researcher with this information. Similarly, the researcher had learned a lot about Stella, her interests and troubles. Although Brinkmann and Kvale (2005) suggested that researchers who are unaware of the contexts and perspectives of research participants' lives should refrain from activity which could be interpreted as therapeutic, the researcher in this case felt that she had a good understanding of Stella's concerns and therefore used her stock of knowledge from this particular interview to make a decision and to offer an explanation. However, the same decision might not be taken if a similar situation arose with a different participant because the context would differ. The danger with qualitative interviews is that through building trust a participant may disclose personal details that they may later regret (Kvale and Brinkmann, 2009). This did not seem to be the case with Stella's interview, it appeared that she had thought about the letter beforehand (it was ready to hand) and then decided, after talking to the researcher for some time, to introduce the letter and talk about it in the context of the interview.

From an epistemic perspective the researcher later considered whether the episode described above could or should be used as "data" within the study. Decision making was informed by considering the section of data as part of the whole of Stella's interview and Stella's interview as a part of the whole study, and finally the extent to which her particular experiences contributed to the overall gestalt. As Stella's concerns were shared by other participants it seemed appropriate to include this data (offered within the context of a recorded interview) within the overall findings.

Paying careful attention to the concerns of participants and prioritising their perspectives over and above those of the researcher is intrinsic to doing "good" IPA (Smith et al. 2009). In research ethics terms, genuine responsiveness and sensitivity to participants' concerns minimises the risk of offence and misinterpretation. According to Shotter (2005:103) inattentive or careless researchers disrespect not only their dealings with participants but at a deeper level they offend and disturb the 'very being' of the person involved. Vulnerable participants, (like Joan and Julia) may feel unable to fully express themselves, and risk turning the problem inwards; 'Is there something wrong with me?' (Shotter, 2005:103). The researcher in the present study therefore understood that she had moral and ethical responsibilities not to ignore the 'involvement obligations'

(Goffman, 1967:115) inherent in the interview situation but also acting throughout data analysis and writing up. Through thinking about and understanding the interactional nature of the interview and the power that researchers hold to honestly reflect as well as to distort another's lived experience (Tappan, 1997), this researcher learned to carefully attend to the ethical dimensions at play in the interview situation and the research process as a whole, whilst attempting to respectfully portray the lives of the people involved in this study.

#### **5.4 Recruitment Procedures**

Following Brunel University, School of Health Sciences and Social Care (SHSSC) Research Ethics Committee approval, Ataxia UK agreed to facilitate a national recruitment strategy. Ataxia UK is a charitable organisation that offers support to its members and funds research into progressive cerebellar ataxia ([www.ataxia.org.uk](http://www.ataxia.org.uk)). Its membership includes people living with progressive ataxia as part of an inherited or idiopathic condition, but excludes those with cerebellar impairments resulting from trauma, or as part of another condition such as multiple sclerosis or stroke. Ataxia UK did not have a formal research ethics review process and accepted the judgement of the School Research Ethics Committee.

The aims and objectives of the study were presented to members of Ataxia UK at their annual conference. Flyers requesting volunteers were also handed out to those who requested further information (Appendix F). Concurrently, the flyer was given to the co-ordinator of the local branches of Ataxia UK to distribute to the Chair of each branch. The flyer was also posted on the Ataxia UK website and placed in the *Ataxian*; a magazine distributed quarterly to all members of Ataxia UK. As noted above, all those who were interested in participating were asked to contact the researcher for written information and a consent form (Appendices D and E). Telephone conversations or e-mail exchanges provided further details about the study and a means of answering questions for those who requested clarification. The recruitment process lasted approximately eight weeks.

An approach was also made to a NHS specialist ataxia centre to ask whether it would be possible to recruit participants from the outpatient clinic. The request was declined because the clinicians and patients were already involved in research. The lead clinician argued that further requests for participation in new projects (patients) and support with recruitment (staff) would overburden both groups.

## 5.5 Participants

Small samples are commonly used in IPA studies because it is only possible to do in-depth, fine grained analysis on accounts from a small number of participants and for further reasons explored in the previous chapter (Smith, 2004, Smith and Osborn, 2008; Smith et al. 2009). Small numbers facilitate the depth of enquiry required to do justice to the richness and the complexity of human lived experience. In accordance with the commitment to an idiographic approach and the emphasis on understanding the perspectives of a particular group of participants, no attempt was made to obtain a representative, heterogeneous sample of participants. The aim in IPA is to recruit a small homogenous sample for whom the research question is significant and meaningful (Smith et al. 2009; Smith and Osborn, 2008). Therefore purposive sampling is usually advocated. Purposive sampling involves the recruitment of participants who have certain features or characteristics which lend themselves to a detailed exploration of the issues the researcher wishes to interrogate; these may be socio-demographic features or specific behaviours or experiences (Ritchie et al. 2003). In purposive sampling, decisions about the sample should be informed by the aims of the study and the existing knowledge or theory about the field of study (Ritchie et al. 2003). This approach differs from the traditional quantitative notion that generating a random or representative sample is necessary for meaningful statistical analysis (Mays and Pope, 1995).

As the focus of this study was the lived experience of progressive cerebellar ataxia and not ataxia as experienced as part of another condition such as multiple sclerosis or stroke, recruitment was intentionally limited to people who were living with a progressive cerebellar ataxia. However, as the progressive ataxias are rare conditions upon which there had been relatively little previous research, the sample could not be informed by existing knowledge, theories or hypotheses specific to these conditions. Thus the sample was purposive in that the type of ataxia was specified and ataxia due to other conditions was excluded. Beyond these constraints a pragmatic approach was taken to recruit key informants who were interested in participating and who had experience relevant to this study.

To be included in the study, participants also had to be 18 years old or over. This was because in addition to posing ethical and methodological challenges particular to their status, the experiences, views and perspectives of children and young people were expected to differ from those of an adult population (Einarsdóttir, 2007). Some experience of physiotherapy was required in order to explore the second aim of the study but the extent of the experience was not defined. This is because although people

living with ataxia may generally be offered physiotherapy, the content, purpose, duration and frequency of this service is not well defined. Therefore excluding potential participants who had less than six weeks of physiotherapy, for example, may have overly constrained the sample and closed off the opportunity to explore the meaning of physiotherapy in whatever form it had been experienced. For the purposes of this study, limited as well as extensive experience of physiotherapy were equally valued. Participants were considered for inclusion if they had been diagnosed with one of the progressive ataxias for more than six months. In keeping with aligned research (e.g. Murray, 2004; Reynolds and Prior, 2003; Thompson et al. 2002) the decision was taken to select participants who were not in the earliest stages of grief or shock immediately following the diagnosis of a long term condition. In line with other work (e.g. Reynolds et al. 2008) participants' reports of their diagnosis was accepted without further medical confirmation. Apart from requesting that potential participants were fluent in English, no further features or characteristics were used to define the sample. Following Brunel University SHSSC Research Ethics Committee guidance, and with permission, GPs were informed of their patient's participation.

Initially 27 people with ataxia expressed an interest in participating in the study. Following provision of the information sheet 15 declined to participate or did not contact the researcher again. Following further telephone conversations and e-mail exchanges, 12 people with cerebellar ataxia were recruited to the study. Although larger than commonly advocated this remains an appropriate sample size for IPA (Smith et al. 2009) and, as discussed in the previous chapter, is consistent with its idiographic orientation. Demographic information about the participants is presented in Table 5.1 (pp. 90). Names have been changed and certain personal details have been blurred to protect anonymity.

Participants lived in England (widespread locations) and were aged between 31 and 73 years. All participants had been diagnosed with a progressive ataxia, although not all participants had a definitive diagnosis. Time since diagnosis with a progressive type of ataxia ranged from a minimum one year to a maximum 23 years. Most participants had lived with symptoms, if not a definitive diagnosis, for over ten years, some for much longer. Five participants lived alone, six lived with their partner, four of whom also lived with dependent children. Harry lived at home with his parents. All participants lived independently except for Bill whose wife was his full-time carer.

**Table 5.1: Participant Demographic Information**

<b>Anonymised Name</b> (marital status)	<b>Age</b>	<b>Type of Ataxia</b>	<b>Time since onset</b>	<b>Occupation</b>	<b>Interview Setting</b>
Ted (married)	Early 40s	Late onset Friedreich's ataxia	About a year	Financial services	Work
Harry (single)	Early 30s	Friedreich's ataxia (diagnosed in adulthood)	Since late childhood	Software consultant	Home
Joan (divorced)	Early 70s	Working diagnosis of episodic ataxia	Uncertain but not more than 15 years	Retired civil servant	Home
Susan (married)	Mid 60s	Cerebellar degeneration	Uncertain but not more than 15 years	Retired housewife	Home
Scott (single)	Early 40s	Cerebellar ataxia, no definitive diagnosis	6 years	Retired military personnel (ill health)	Ataxia UK HQ
Graham (single)	Early 40s	Cerebellar ataxia, no definitive diagnosis	Many years but more significant symptoms over last decade	Unemployed (looking for work)	Ataxia UK HQ
Hugh (married)	Early 50s	SCA 6	Many years but diagnosed in 2004	Administrator	Home
Stella (separated)	Mid 50s	Cerebellar ataxia, no definitive diagnosis	Uncertain but not more than 15 years	Retired	Home
Bill (married)	Late 50s	Cerebellar ataxia, no definitive diagnosis	Symptoms for many years, diagnosed 13 years	Retired counsellor (ill health)	Home
Toby (married)	Mid 50s	Idiopathic cerebellar ataxia	4 years	Retired semi-skilled manual worker (ill health)	Home
Julia (unknown, lives alone)	Late 60s	SCA 6	22 years	Retired service industry worker	Home
Jim (married)	Late 40s	Cerebellar ataxia	23 years	Administrative manager	Ataxia UK HQ

## 5.6. Development of the Interview Guide

The most common approach to collecting data suitable for IPA is through an in-depth semi-structured interview which usually lasts for an hour or more (Smith et al. 2009; Smith and Osborn, 2008). This flexible data collection tool allows a detailed exploration of the phenomenon of interest. The researcher is able to pursue salient topics as they emerge in the account and to modify questions in light of participants' responses (Smith and Osborn, 2008). Consistent with the epistemological assumptions underlying IPA,

knowledge and understanding of a participant's lifeworld is developed from first-hand information gathered through time spent in the field with the participant (Smith and Osborn, 2008). This means of data collection allows the researcher to "get close" to that which is being studied, facilitating as far as possible entrance to the psychological and social world of the participant, helping the researcher understand, or get a sense of, what it is like to experience the phenomenon. In this way the relationship between interviewee and interviewer is seen as collaborative and interdependent; both share the responsibility for the direction the interview takes but as far as possible the participant should lead the way (Kvale and Brinkmann, 2009; Packer, 2011). This approach is consistent with Heideggerian phenomenology which has at its core an aim to provide the maximum opportunity for the subject to reveal itself 'as itself' (Larkin et al. 2006:108). It is therefore important that the interview is structured to facilitate rapport-building between the researcher and the participant and to give a strong sense of control to the interviewee (Smith and Osborn, 2008).

In developing the interview schedule for the present study, previous work concerned with understanding the lived experience of long term conditions and other published IPA studies and texts (e.g. Reynolds and Prior, 2003; Smith and Osborn, 2003; Dean et al. 2006; Smith and Eatough, 2006) were reviewed to gain an understanding of the scope and sort of questions that might be useful in this type of research. The purpose of the literature review in IPA is to learn about the phenomenon of interest and to identify a gap in what is known about the particular topic but the literature is not subsequently used to inform data collection in a rigid way (Smith et al. 2009; Smith, 1999). The researcher therefore starts with some understanding of the area of interest, and some questions, but unlike quantitative research, existing literature is not used to develop hypotheses which are then supported or rejected by the findings of a study.

An interview guide or schedule ensures that the researcher has mapped the area considered important to cover in the interview, and that careful consideration is given to potentially difficult topics and the placement of sensitive questions (Smith et al. 2009; Smith and Osborn, 2008). In the present study a broad set of questions was firstly constructed as a frame of reference for what was then the intended focus group (Appendix Ga).

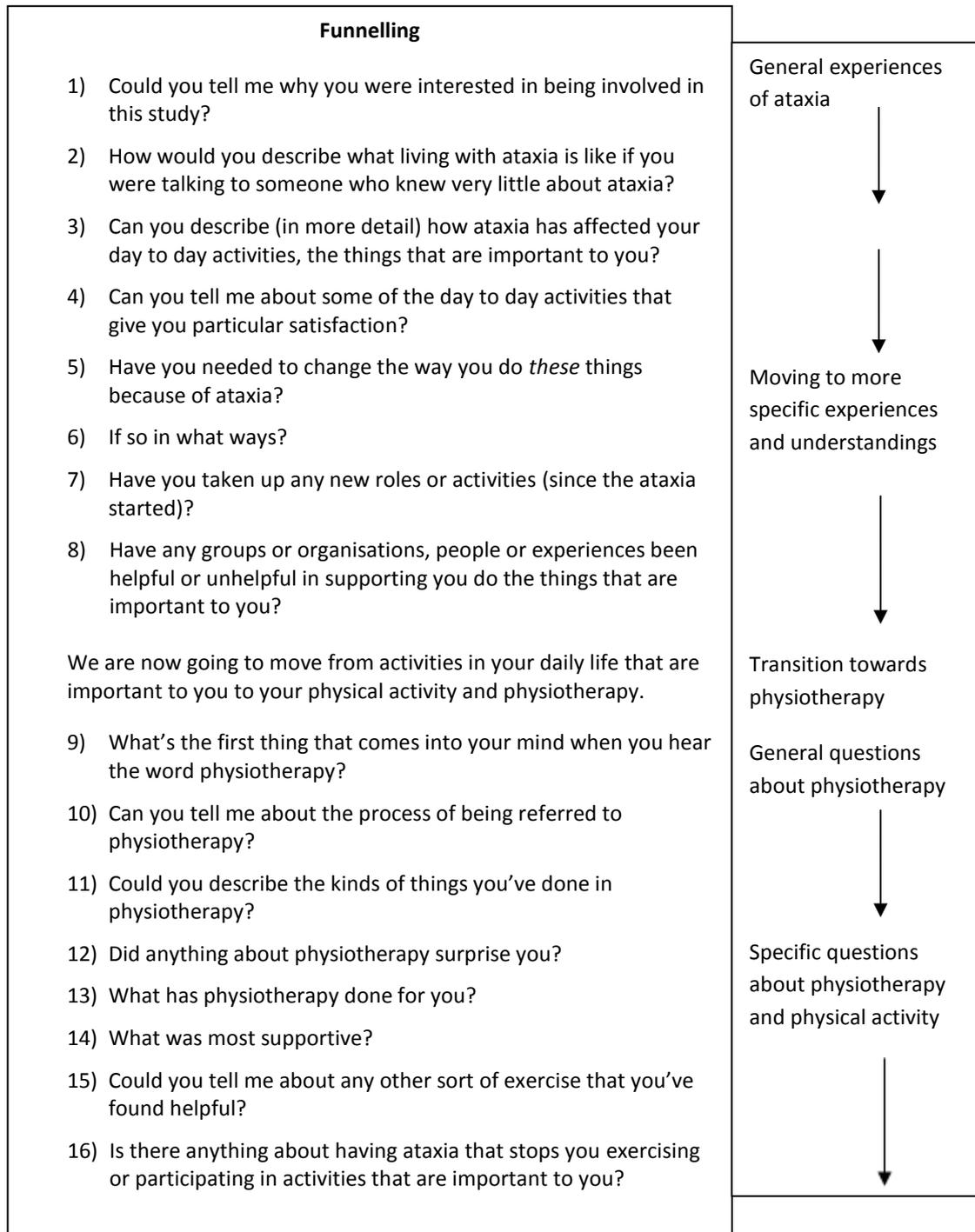
Once a general idea about the shape of the interview schedule was agreed with peers and supervisors, a first draft of the interview guide was developed by the researcher and reviewed by the supervisors (Appendix Gb). A second draft was developed in response to further comments, reconsidered priorities and re-ordering of questions (Appendix Gc).

The initial draft clearly reflected the researcher's interest in physiotherapy; the restructuring of the interview questions (and the subsequent prioritisation of the participants' concerns and interests during data analysis) documents how this thinking changed as the study evolved.

Figure 5.1 (pp. 93) demonstrates how funnelling (recommended by Smith et al. 2009 and Smith and Osborn, 2008) was built into the final draft of the interview schedule to elicit general views about the experience of living with ataxia as well as responses to more specific questions about the possible effects of ataxia. Questions which explored the participant's experience of physiotherapy and exercise then followed, once again moving from the general to the particular. At this stage the interview guide looked very structured and detailed but after the first interview it was used more flexibly (discussed below). In keeping with the theoretical orientations of IPA, the interview questions were created to facilitate a particular type of conversation (Kvale and Brinkmann, 2009) grounded in a 'heuristic framework' which was directed towards finding out or uncovering experiential understandings of the topic of interest (Flowers et al. 2000:288). In this way the interview guide represented possible paths on a journey of discovery rather than clear signposts for the direction of travel.

Prompts were also built into the interview guide. Kvale and Brinkmann (2009) suggested that follow up questions are critical to the interview process to develop more detailed or participant-led responses but are more often than not constructed on the spot, in direct response to what has just been said. In addition silence or simply general encouragement (nodding or non-specific articulations such as 'hm, mm ...') was considered just as important as verbal communication in fostering elaborations or more in-depth consideration of the topic. So, whilst prompts were scripted into the interview guide, in practice the prompts used were usually re-phrasings or amplifications of the initial question.

**Figure 5.1 Semi-structured Interview Guide Demonstrating Funnelling**



As the researcher developed more confidence and experience at interviewing, follow up questions as well as periods of silence were used more naturally or intuitively to gently nudge the participant towards providing a richer account. This transition is consistent with Kvale and Brinkmann's (2009) view that as interviewers become more skilful in their craft they move away from an initial heavy reliance on the interview guide and instead use their sensibility for what feels right in the moment to help them decide what to do

next. The pilot interview (see below) helped in the development of this process. De-briefing questions were included at the end of the interview by asking if the participant had anything further to add. This approach provided space for the participant to raise issues that might have concerned them during the interview and also helped to dispel any tension or anxiety that the participant may have encountered in talking about very personal experiences (Kvale and Brinkmann, 2009). Further opportunities for discussion were offered once the recorder was switched off. If new and relevant topics were discussed at this point the participant was asked if handwritten notes could be taken. Switching the recording device back on seemed too intrusive when the purpose of de-briefing was to prioritise and discuss the participant's concerns and perspectives about their experience of the interview.

### **5.7 Data Collection**

Interviews were offered in participants' homes, at their workplace or a local community facility such as the Ataxia UK offices or public libraries. Although home might be considered ecologically valid in terms of conducting IPA i.e. by providing the researcher with an opportunity to meet the participant in context, home can be problematic for confidential interviews if others are present or if mobility problems make tidying up difficult. Therefore in recognition of the potential concerns of participants in this regard alternative venues were offered. As the interviewer was working unaccompanied, lone working policies were also used to minimise risk (Appendix H).

### **5.8 Pilot Interview**

In IPA research, although considerable work goes into the development of the semi-structured interview guide in terms of organisation, wording and placement of sensitive topics, it is not expected or encouraged that interview questions are applied rigidly or in a specified sequence. The reason for this is because an unbending adherence to the interview guide could block the emergence of unexpected topics which directly reflect the interests and particular concerns of the participant (Smith and Osborn, 2008). The researcher is expected to explore these topics "on the hoof" so that a richer account emerges from the interview than could be anticipated in advance. In order to be this flexible in an interview situation, the researcher has to be familiar with the interview guide to enable movement between topics in response to the interests of the participants. Smith et al (2009) and Smith and Osborn (2008) advised memorising the interview schedule in advance to facilitate this process. Furthermore, as mentioned above, the researcher requires a certain level of confidence and experience with the

interview process in order to facilitate a smooth transition between questions that will not necessarily follow the planned order, and to omit questions that are not relevant for particular participants without worrying about not covering the ground. The pilot interview was directed towards achieving this sort of fluency and flexibility.

The following aims were developed for the pilot interview:

To try out the draft interview guide and to identify problems with its construction and use in the field.

To provide the researcher with an opportunity to practice interviewing and using the interview guide.

To give feedback to the researcher about interview technique.

The first person who responded to the recruitment material and who consented to participate was interviewed for the pilot interview. This was Ted, in his early 40s, he worked in financial services and he was diagnosed, a year before the interview, with late onset progressive cerebellar ataxia. Ted was interviewed at his place of work. The interview schedule was memorised and followed as far as possible, reference to a paper copy was made where necessary. The interview was recorded using a digital voice recorder and transcribed. Careful scrutiny of the interview transcript (researcher and supervisor), the questions and responses, demonstrated that the researcher required expert feedback from her supervisor to hone her interview technique. Figure 5.2 (pp. 96), an extract from the pilot interview transcript, demonstrates several issues with the questions asked by the researcher.

A close look at Figure 5.2 (pp. 96) suggested firstly that the researcher missed an opportunity to explore fatigue in more depth. Follow up questions could have prompted Ted to explain what he meant by *'you end up making problems'*. The researcher could have asked Ted to explain what these *'problems'* were, why he found it difficult to relax and what he meant by *'a continual circle'*. Also it might have been useful to find out who said that Ted was not leaving work early enough, he might have been hinting here about his family or perhaps concerned work colleagues, or even his own opinion. The final question *'Is that because you're more tired?'* is a leading question, a pause would have been useful to allow Ted more time to consider his answer, a better question would have been *'In what ways does it make a difference to your home life?'* This may have prompted Ted to provide a more expansive answer.

**Figure 5.2: An Extract from the Pilot Interview Interview Transcript**

*Ted: One of the problems with ataxia is when you're tired you tend to be more unsteady. [...] it's sort of self-defeating because when you're tired you end up making problems, you can't really relax, it's just a continual circle.*

*Interviewer: Have you developed any strategies to cope with that? Have you changed anything in your life to help you manage that?*

*Ted: Try to leave work earlier*

*Interviewer: Mmm*

*Ted: Some people say not early enough, but it is earlier than I used to.*

*Interviewer: Okay. And has that made a difference?*

*Ted: It makes a difference to home life, yes.*

*Interviewer: Yeah. Is that because you're less tired?*

*Ted: Um ... yes.*

As a physiotherapist the researcher had over fifteen years of clinical experience which included interviewing patients as part of standard assessment and treatment procedures. However, having experienced a predominantly biomedical training at undergraduate level and having a quantitative research background at Masters level, it was not surprising perhaps to find qualitative interviewing a difficult skill to master initially. The clinical situation is directed towards a quick and highly directed “subjective” assessment (interview) designed to identify key problems and to prioritise areas for immediate “objective” (physical), time limited examination. Open questions and prompts such as ‘How do you feel about that?’ are not necessarily part of a physiotherapist’s currency, particularly on first meeting a patient. In this context the clinical interview could be understood as a means of ‘knowledge collection’, the clinician as ‘miner’ digging down for objective facts which bear little or nothing of the person who uncovers them (Kvale and Brinkmann, 2009:48).

The problems that this researcher encountered in developing a less directive interviewing style were mirrored by those of another physiotherapist who conducted a study using IPA (Dean et al. 2006). In a similar way to Sarah Dean, it took practice and expert feedback for this researcher to develop effective interview skills necessary for the

present study. With practice, the researcher moved away from being oriented towards 'knowledge collection' and towards 'knowledge construction', the interviewer as 'traveller' (Kvale and Brinkmann, 2009:48). In this analogy, the interviewer is understood as taking a journey where s/he falls into conversation with others who, in response to the traveller's questions, talk about their lives. The traveller makes sense of and interprets these stories by retelling them to others. New knowledge is formulated in these stories but the traveller or interviewer also changes by learning to look afresh at previously taken-for-granted understandings of the world. This well-known metaphor works well with Smith's (2007) explication of the hermeneutic circle. Here, too, the researcher-interviewer travels; moving round the hermeneutic circle in the interview and when working with the data back at base, using hermeneutic questions to work out preconceptions, prioritising new knowledge, developing further questions and thereby eliciting a richer understanding of the phenomenon of interest.

Reviewing the transcript from the first interview showed that the researcher had difficulty using the interview guide flexibly, tended to ask closed as well as leading questions, rather than hermeneutic questions, and at times failed to probe potentially interesting or emerging issues. In addition to being a novice at this sort of interviewing and finding it difficult, it is also possible that the researcher was still in clinical mode, troubled by feelings about being overly intrusive and therefore resisting entering the client's lifeworld. It is possible that in this early interview the researcher was struggling to forge a researcher identity whilst trying to resist the natural inclinations of a dominant therapist identity. The researcher's lack of confidence and experience in this type of interviewing did not perhaps initially facilitate full engagement with the interview process. The following extract from fieldwork diary notes reflects this discomfort: *'Probing for deeper answers felt intrusive. It didn't feel right. Felt I had nothing to offer in return.'*

The problems described here are not uncommon and possibly stem from needing to find a 'comfortable research persona' (Smith et al. 2009:67). Careful review of the first transcript enabled the researcher to reflect on her interview style and listening skills. Phrases such as 'Can you tell me more about that?', 'In what ways ...?', 'Can you add to that?', 'How did you feel about that?' were identified as means of assisting this process (Kvale and Brinkmann, 2009; Smith et al. 2009). No changes were made to the interview guide as a result of the first interview. Despite the problems encountered in this interview, relevant and important features unique to Ted's circumstances emerged and the themes that were later developed from this interview foreshadowed some of those that were to emerge in the interviews with other participants. Therefore the pilot interview data were incorporated into the main study.

In keeping with the view that research interviews are pragmatic enterprises and that proficiency can be learnt through practice (Kvale and Brinkmann, 2009), the researcher developed a better understanding of the interview process overtime and became more skilful at sensitively tuning into important and interesting topics. As the researcher became more experienced and confident in this type of interviewing the opening question was able to be used as a jumping off point for the rest of the interview, and there was less dependence on following the question format as presented in the interview guide. Fieldwork diary notes made after the second interview reflect this belief:

*'Happy to let him speak, didn't use the interview guide very much, hoped that the 'ground' was in my head. Didn't cover all the areas but I think that's ok, got a good picture.'* (Fieldwork diary entry, May 2007)

A longer extract from Hugh's interview is included in Appendix I to demonstrate improvements in interview technique and the extent to which Hugh, rather than the researcher, shaped the interview.

This section accounted for the development of the interview guide and indicated how the researcher improved her interview technique through reflexive analysis and practice in the field. In this sense the pilot interview achieved its aims and it was appropriate at this stage to move on to the main study.

## **5.9 Data Recording and Transcription**

IPA is embedded within the philosophical assumption that individuals experience the same phenomenon differently i.e. that there are multiple realities of, in this case, the experience of living with ataxia. IPA intentionally reports these multiple realities by using multiple quotations of the actual words of participants and by presenting the differences and as well as the similarities of experience both within and across individuals (Smith et al. 2009). Therefore the interviews in this study were captured using a digital voice recorder and a high quality microphone. All participants were interviewed individually except for Graham and Scott who, following their preference, were interviewed together (discussed below). The interviews lasted approximately an hour (mean 67 minutes; range 53-104 minutes) and resulted in 12.3 hours of recorded data. Data collection took 3 months (May-August 2007). Field notes were made as soon after the interview as possible. These notes were incorporated into a reflexive diary which recorded the researcher's immediate thoughts and feelings about the interview and, as identified in

chapter 1 (Introduction), acted as a chronological resource and a way of mapping the development of these thoughts, tentative analyses and preoccupations over time.

Each MP3 file was downloaded and sent via secure data transfer to an independent transcriber who produced word files containing the transcription of each interview. Notes written when the recorder was switched off were added to the word document of the transcribed interview. Transcription was at the semantic level; all the words spoken, including false starts, pauses, laughter and any other significant events that occurred during the interview. A more detailed transcription such as that used for conversation analysis is not recommended for research conducted in the IPA tradition (Smith et al. 2009). This is because for IPA the emphasis is on the meaning of the content whereas for conversation analysis the interest lies in analysing the structural aspects of naturally occurring verbal interaction (Drew, 2003). Following transcription, each account was listened to several times to start the process of immersing the researcher in the data. Changes were made to the transcript where necessary to correct mis-transcription of technical words and indistinct articulations that only became clear through repeated listening. Identifiable information was fully anonymised and pseudonyms were allocated to each participant.

### **5.10 Data Analysis**

Consistent with its phenomenological and interpretative roots, IPA aims to provide a rich account of a person's experience which goes beyond first level description and attempts to do justice to the person in their entirety (Smith and Osborn, 2003). IPA does not aim to produce an objective or definitive account and does not make any claims about being able to directly access a person's experience, only to access an account of the experience as the participant makes sense of it during the interview (Smith et al. 2009; Smith and Osborn, 2008). The resulting narrative is thought to be revealing, important and of value, not because it lays bare the essence of a particular phenomenon, which would be impossible from a Heideggerian perspective (Finlay, 2003a), but because the stories people tell themselves and others about their lives say something about their constructed but uniquely situated identities (Smith, 2003). The meanings derived from this purposeful talk are wholly context-dependent and are not meant to create broadly applicable knowledge. The analysis aims to illuminate an 'insider's perspective' (Conrad, 1987:2) but this is inherently difficult and can never be fully realised (Smith and Osborn, 2008).

Furthermore, participants may have trouble expressing themselves and their experiences and they may choose to avoid revisiting sensitive or painful topics. The focus of the analysis therefore is not simply on content but also on unravelling complex metaphorical references, hidden meanings and unintentional leaking of information. Furthermore, as discussed previously (chapters 1 and 4), the researcher's own conceptions (ideas, imaginings), what Smith (2004:45) refers to as the 'biographical presence' of the researcher, are needed to make sense of what is said. This sort of enquiry and analysis requires a firm reflexive stance not simply to help the researcher unravel his/her own pre-understandings but to allow participants to '*reveal themselves* through acts that frustrate the researcher's preconceived ideas' (Kvale and Brinkmann, 2009:243, emphasis added).

As discussed in Chapter 1, Finlay (2008) has likened the tension involved in this interpretative process to a complex dance where the researcher carefully negotiates, through improvised steps, a path that identifies assumptions and brackets them off whilst at the same time using them creatively to develop further hermeneutic questions that remain faithful to the phenomenon itself. This complex intertwining of bracketing and reflexivity is closely connected to the way in which the hermeneutic circle works in IPA (Smith, 2008). The understanding of the interview as a dynamic and co-constructed event is therefore taken forward into the data analysis process. Knowledge is built through the conversational and relational dimensions created between the researcher and the participant in the interview and subsequently between the researcher and the text (Kvale and Brinkmann, 2009).

Data analysis was therefore guided by an attitude of openness and a willingness to dwell in the data, consistent with the approach taken towards data collection. The focus remained on participants' attempts to make sense of their experience (Smith et al. 2009). In practice, the researcher closely followed the guidelines set out in Smith and Osborn (2008) and Smith et al (2009). Whilst this approach to analysis may seem formulaic, the primary purpose of the staged progression is to facilitate a sustained engagement with the text. The process may appear linear when written up but the researcher intentionally sets out to develop an iterative relationship with the data; moving back and forth between different levels of the analysis of each case, and across cases and levels in the later stages, building familiarity with the text to ensure that the findings are grounded in the data.

### **5.10.1 Developing Themes from the First Case**

The manuscript was prepared for analysis by numbering each line and page of transcription, and by creating wide margins and a short line of central text. The transcript was closely read several times to develop as much familiarity as possible at this early stage, and the left hand margin of the transcript was used to document interesting or significant statements. Smith and Osborn (2008) have described this phase as close to a free textual analysis, there are no rules about what should be written down; it might be an interesting phrase, or linguistic device, a summary of a piece of text, a preliminary interpretation or initial thoughts. The researcher may comment upon similarities in the text, as well as contradictions and ambiguities.

The second phase of the analysis involved re-reading the text several times and documenting emerging themes in the right hand margin. Concise phrases were used that tried to capture the essence of what was said, focusing on what seemed to be important. The themes are not definitive at this stage, but should be at a higher level of abstraction than the impressions written in the left hand margin (Smith and Osborn, 2008).

The third stage of analysis involved collating all the potential themes from the right hand margin in chronological order as they emerged in the original transcript. Connections were identified across themes and similar themes were clustered together (subordinate themes). Superordinate themes which best captured the subordinate themes and the most strongly emerging experiences were finally developed and identified. In accordance with Smith and Osborn (2008) themes were based on their ability to illuminate the experience rather than on their frequency or prevalence within the data. Each subordinate theme was tagged to demonstrate where the theme could be found in the account therefore maintaining the link between the data and the analysis. In this way, the researcher was constantly checking the interpretation with the raw material of the transcript, making sure that the sense making of the researcher was grounded in what the participant actually said. Primacy throughout remained with the data.

Consonant with the commitment to an idiographic approach, the final stage of the analysis involved the translation of the themes into a narrative account, using verbatim extracts to trace and support the analytic process. By remaining faithful to the individual, the final narrative account should stand alone. Subsequent analyses from different participants about the same phenomenon should not be artificially manufactured to align with the perspectives or experiences of other participants or to fit a particular formula for analysis that worked with a previous account. In this way, the researcher upholds the

commitment in the idiographic approach, to speak of individual existence rather than incidence, and to look for similarities as well as differences in individuals' experiences (Smith et al 2009; Smith, 1999; Smith et al. 1995).

The narrative account should realise the hermeneutic stance taken in IPA studies. The empathetic hermeneutic is concerned with identifying with or developing a sensitive understanding of the character and nature of the experience. The aim here is to describe the participant's world, to convey what the experience is like; the emic position. This interpretation is followed by a more critical stance, the questioning hermeneutic, where the researcher probes the text, looking for hidden meaning, unintentional commentary and motivations; the etic position (Reid et al. 2005; Larkin et al. 2006). The interpretations made in this stage of the analysis are ones that participants are unlikely to have foreseen or acknowledged themselves (Smith and Osborn, 2008).

An example of the process described above is presented in Appendix J. It demonstrates how the analysis was undertaken and illustrates the development of the superordinate themes for one participant, Jim, and how these were incorporated, albeit, in a slightly different format, into the overall master super-ordinate themes for this study.

### **5.10.2 Continuing the Analysis with Other Cases**

In keeping with the commitment to the idiographic stance of IPA, each individual transcript was analysed in the same way before moving on to examine the next case. Smith and Osborn (2003) suggested that subsequent cases could be analysed using the themes of the first case as a guide or by analysing each case from scratch. More recent work has however articulated a stronger commitment to an idiographic approach (e.g. Smith et al. 2009), therefore in this study each case was analysed afresh. Emerging themes from each case were not explicitly referred to during the analysis of each subsequent case. However, the researcher was unlikely to be able to fully disregard the findings of previous analyses, and in accordance with Smith et al (2009) an attempt was made to set aside the impressions that had emerged from the previous case(s). Early difficulties with this process (for example the researcher's strong preconceptions about the relative unimportance of participants' accounts of their symptoms) are described in more depth in chapter 6 (The Embodied Experience of Living with Progressive Cerebellar Ataxia). However, new topics emerged by preserving an attitude of openness and by paying careful attention to each transcript in its own right.

### 5.10.3 Analysis of the Joint Interview

Whilst paired interviewing is uncommon in IPA, it is not unique to this study (see Macleod et al. (2002) and McIntyre and Reynolds (2012) as examples where more than one participant was interviewed at a time). Conducting an interview with two people simultaneously obviously creates a socially complex situation that requires skilful facilitation by the researcher (Smith et al. 2009). The joint interview in the present study occurred in response to Graham's and Scott's preference to be interviewed with another person living with a progressive cerebellar ataxia. The joint interview was undertaken just over halfway through the data collection period.

During data collection the researcher took care to ensure, if it did not happen naturally, that each participant had the opportunity to offer their views. For example comments such as 'How about you Graham?' and 'Graham you're nodding there?' helped bring in the other participant if one of them had been dominant for a while. On the whole, though, the participants developed a conversational style that required only limited input from the researcher, for example Scott continued the thread developed by Graham; '*I could say that I find similar*', or Graham provided his own example of a topic raised by Scott; '*Yeah, I'd agree with that*'. The two participants were also not afraid to disagree; for example Graham clearly stated how his symptoms differed from Scott's. In response to a direct question about whether Graham had a similar experience he said '*Not really. I don't*' and then continued to explain how his experiences differed.

Data analysis for this interview proceeded in a similar way to that undertaken with the other participants. In keeping with the commitment to understanding the unique perspectives of the participants, each account was analysed individually, focussing primarily on the intrapersonal data rather than the interpersonal data. Subordinate and superordinate themes were separately developed for each of these two participants. However, with reference to Smith (2004), the accounts were analysed a second time to look at how the two participants interacted and whether this influenced the data. This analysis demonstrated that interactions between the two participants helped to amplify or develop ideas, and there were a few occasions where the participants engaged in collaborative sense-making (e.g. Graham: '*That's it! Yeah, that's good,*' in response to an elaborate example provided by Scott).

### 5.10.4 Cross-Case Analysis

Unlike the case-by-case analysis, the cross-case analysis involved overt referral to all cases looking for differences as well as similarities, identifying patterns, re-working and

renaming themes as a deeper understanding of the data developed (Smith et al. 2009). In practice, this involved drawing on the narrative summaries, the lists of subthemes and superordinate themes for each participant, as well as revisiting the original transcripts and identifying the richest and most illuminating quotations to support the development of super-ordinate themes for the whole group. Five final or master super-ordinate themes were developed and these represented the key emerging themes for the corpus. These master themes are presented in Table 5.2 (pp. 105). Subthemes are nested in each super-ordinate theme. The master super-ordinate themes are presented here to give an overarching perspective on the findings.

**Table 5.2 Final Super-ordinate Themes and Subthemes**

Theme	Super-ordinate Theme	Description	Subthemes	Description
1	<i>'I was like a pinball, I was bounced off this wall, went to that wall'</i> (Toby)	The embodied experience of living with progressive cerebellar ataxia	<i>'Everything is uncoordinated'</i> (Bill)	Disrupted embodiment
			<i>'It's like you're trying to avoid hitting them but you're actually going towards them'</i> (Scott)	Disrupted embodiment: agency and cognition
			<i>'It just takes that much out of you physically and mentally, just totally shot'</i> (Toby)	Fatigue and cognitive overload: disturbing consequences of disrupted embodiment
2	<i>'I don't want to seem handicapped in any way'</i> (Stella)	Identity, stigma and disrupted embodiment in public spaces and places	<i>'I won't do things that might cause offence'</i> (Julia)	Unwilling focus on stigmatising forces
			<i>'I wouldn't go outside [...] with a stick'</i> (Stella)	Rejection of stigma symbols
			<i>'I'm being put to one side really'</i> (Hugh)	The discrediting world of work
			<i>'[He] holds me by the scruff of the collar'</i> (Julia)	Family who stereotype/judge
3	<i>'The cerebellum should be a tight cauliflower and mine was two sticks of celery'</i> (Julia)	Lifeworld meets biomedicine: a complex juxtaposition	<i>'I go and see the neurologist and I get another adjective, but I don't actually get a definitive answer'</i> (Graham)	Making sense of ataxia through a medicalised lens
			<i>'I think my brother's got it'</i> (Hugh)	Ataxia in the family
4	<i>'Whenever it gives you a problem find a way round it, or fix it, you know'</i> (Harry)	Wresting control in the face of uncertain and changing forces	<i>'You're not on your own'</i> (Scott)	Seeking out information and drawing support from informed others
			<i>'Focus on what you can do, not what you can't do'</i> (Toby)	Taking a stand: personal philosophies for living with ataxia
			<i>'When I do something, I do it in bite size'</i> (Scott)	Finding ways to preserve valued roles and interests
5	<i>'It makes me feel better that I'm actually doing something'</i> (Ted)	Exercise: a multifaceted contributor to managing life with ataxia	<i>'it does make you feel good and you've got an awful lot of control over things'</i> (Scott)	Exercise as a means of seeking control and sustaining a positive sense of self
			<i>'You get about 6 weeks and then you're discharged and sent home to do your exercises on your own'</i> (Stella)	Physiotherapy – at times overly one-dimensional and inexpertly focussed on the impaired body

Recurrence across cases was measured in keeping with good IPA practice for larger samples (Smith et al. 2009). Each of the five super-ordinate themes was present in at least 8 of the 12 accounts; this was considered sufficient to classify each theme as recurrent (presented in Table 5.3, pp. 107).

At this stage it was considered that the most important elements of each participant's account had been captured and organised and although there are no formal means of measuring or identifying when an analysis is good enough or complete (Smith et al. 2009), it felt as if a coherent and in-depth analysis of the lived experience of progressive cerebellar ataxia had been elucidated for this group of participants. Therefore a final interpretative narrative was written using extended quotations from participants to introduce, analyse and discuss each master theme. Although these are the common themes, unique experiences (supported by direct quotations) are discussed in-depth in the narrative account of each master theme. Consistent with IPA (Smith et al. 2009) and qualitative analysis and writing more generally (Dickie, 2003) data analysis and interpretation continued even at this late stage. Each of the five super-ordinate themes is presented in detail in the following chapters and discussed with reference to the extant literature. Although this is perhaps uncommon (to present the findings and discuss them with reference to the literature in the same chapter) it is not unheard of and it is not considered inappropriate for IPA research as long as the idiographic orientation is followed, and the findings and the discussion are grounded in participants' accounts (Smith et al. 2009).

**Table 5.3 Indication of Prevalence for Each Participant for Each Super-ordinate Theme and Associated Sub-themes**

Participant	Super-ordinate Theme 1 Embodiment (n=12)			Super-ordinate Theme 2 Stigma (n=8)				Super-ordinate Theme 3 Biomedicine (n=12)		Super-ordinate Theme 4 Control (n=11)			Super-ordinate Theme 5 Exercise (n=12)		Total n=14
	Subthemes (3)			Subthemes (4)				Subthemes (2)		Subthemes (3)			Subthemes (2)		
Bill	✓			✓				✓		✓			✓		8
	✓			✓				✓	✓	✓	✓	✓		✓	
Stella	✓			✓				✓		✓			✓		9
	✓	✓		✓	✓			✓	✓	✓	✓			✓	
Harry	✓			✓				✓		✓			✓		12
	✓	✓	✓	✓	✓	✓		✓	✓		✓	✓	✓	✓	
Ted	✓							✓					✓		4
	✓		✓					✓					✓		
Scott	✓							✓		✓			✓		10
	✓	✓	✓					✓	✓	✓	✓	✓	✓	✓	
Toby	✓			✓				✓		✓			✓		10
	✓	✓	✓	✓		✓		✓	✓		✓		✓	✓	
Graham	✓							✓		✓			✓		10
	✓	✓	✓					✓	✓	✓	✓	✓	✓	✓	
Julia	✓			✓				✓		✓			✓		11
	✓	✓	✓	✓			✓	✓	✓		✓	✓	✓	✓	
Joan	✓							✓		✓			✓		8
	✓	✓	✓					✓	✓		✓	✓	✓		
Jim	✓			✓				✓		✓			✓		9
	✓			✓	✓	✓			✓	✓	✓		✓	✓	
Susan	✓			✓				✓		✓			✓		11
	✓	✓	✓	✓			✓	✓	✓	✓	✓			✓	
Hugh	✓			✓				✓		✓			✓		9
	✓	✓	✓			✓		✓	✓	✓	✓			✓	

### **5.11 Judging the Rigour and Quality of IPA**

Data analysis in IPA attends to an underlying method but is shaped by the interpretative work carried out by the researcher at each stage (Smith and Osborn, 2008). The data presented should support the claims made by the researcher but it is unlikely that an independent analyst would identify exactly the same themes in exactly the same way. Working from a Heideggerian perspective, phenomenologists understand that different analysts would interpret a particular phenomenon using personal contexts and experiences and therefore the emphases and precise articulations of the findings would differ (Finlay, 2002).

As noted in chapter 3 (Literature Review) there are many ways to judge the quality of qualitative research and the debate continues about which terms to use to describe quality, what constitutes quality and how it should be evaluated (see for example Lincoln and Guba, 1985; Elliott et al. 1999; Spencer et al. 2003; Dixon-Woods et al. 2004; Yardley, 2000; 2008 and Kvale and Brinkmann, 2009). Although the debate is on-going, some sort of consensus seems to have been reached about how qualitative health research should be judged. The thrust of the argument is marked by a move away from advocating simplistic tick box approaches which are incapable of capturing the complexity of much qualitative work (Spencer et al. 2003), and in themselves do little to guarantee rigour (Barbour, 2001). Constructs traditionally allied to quantitative research that are less meaningful in the qualitative paradigm, such as objectivity, reliability, validity and representative samples, have on the whole been replaced, or at least refashioned, by quality indicators that are more consistent with the philosophical constructs underpinning qualitative inquiry (see for example Yardley, 2000; Spencer et al. 2003; Madill et al. 2000). Furthermore, these criteria seem to be best judged in a process oriented rather than an outcome oriented way (Morse et al. 2002; Kvale and Brinkmann, 2009). Yardley's (2000, 2008) four key dimensions for evaluating qualitative health research seem to capture the majority of what is considered important in judging the quality of qualitative research. These quality dimensions are; sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance. Smith's (2011a, b) IPA-specific criteria are appropriate for judging the particular qualities or flaws of the present study. It is the principles derived from both Yardley (2000, 2008) and Smith (2011a, b) that have been attended to in this study. The extent to which these principles have been upheld is discussed in chapter 11 (Discussion).

## **5.12 Summary**

This chapter presented an overview of the procedures undertaken in order to answer the research questions. In an effort to be as transparent as possible the data analysis process was explained in detail and, with reference to appendices, the process of analysis from raw data to fully worked-up master super-ordinate themes was demonstrated. Each of the following chapters (6-10) present and discuss the five master super-ordinate themes which constitute the main findings for this study.

## Chapter 6

### Super-ordinate Theme 1

*'I was like a pinball, I was bounced off this wall, went to that wall' (Toby)*

**Description: The embodied experience of living with progressive cerebellar ataxia**

#### 6.1 Introduction

Unlike much phenomenological research where the body is absent (Habermann, 1996; Finlay, 2006), the bodily experience of living with ataxia claimed prominence in this study. The phenomenological perspective afforded a person-centred view of embodiment not usually admitted by a traditional biomedical orientation. Participants' accounts revealed novel and richly textured ways of understanding ataxia as an embodied phenomenon. The body was an insistent presence in participants' accounts of their everyday lives and, rather than being 'swallowed up' in the execution of tasks and postures (Merleau-Ponty, 2002 [1945]:115), their bodies took on a new significance, becoming contingent in all the participants' activities and projects. This theme offers a detailed account of the bodily experience of living with ataxia and the meaning this held for participants in this study.

Data analysis was not a straight forward process. Initially, the analysis was informed entirely from the perspective of the physiotherapist-researcher. The data discussed in this theme were at first dismissed as "not phenomenological" and stored in a file labelled "symptoms". The researcher unintentionally analysed the data through a physiotherapist's lens and in doing so perhaps demonstrated the difficulty, particularly for a novice researcher in this field, to prioritise and foreground participants' perspectives over and above those of the researcher. At the time, (i.e. during the initial processes of the analysis) it seemed entirely appropriate to decontextualise participants' accounts, even going so far as to classify "symptoms" under familiar biomedical subheadings such as dysarthria, dysynergia and dysmetria.

A small insight, the indescribable experience of living with ataxia, seemed to offer a way into the data which led to the development of more informed hermeneutic questions as the analysis progressed. Participants seemed to find it difficult to communicate and frame their experiences in ways that could be easily understood by others. Careful and repeated readings of the text provoked a reappraisal of the preliminary analysis and drew the researcher's attention to the abundant use of figurative language embedded in participants' accounts. Metaphors and similes seemed to help participants articulate

particular aspects of their experiences that seemed difficult to put into words and worked to draw the researcher into the participants' world. Visualising and exploring participants' descriptions through movement enabled the researcher to engage more deeply with the text. Previously taken-for-granted assumptions about "symptoms" began to be seen in a new way and, by dwelling in the data, it became possible to re-imagine ataxia within the context of the participants' embodied lived experience.

Radley (1993) argued that metaphors work not only through direct comparison of how one thing is similar to another, but also (and this is what helped push the analysis of this data to a deeper, more hermeneutic level), through illustrating how 'one aspect of the experience is *invigorated* by another' (Radley, 1993:112, emphasis added). Toby, for example, by comparing the way he moved to the near random trajectory of the ball in a pinball machine, concisely and powerfully expressed the loss of agency he experienced as part of living with ataxia. The pinball reference pushed the researcher away from understanding Toby's chaotic movement as another example of disordered walking, and towards a deeper analysis that came closer to a more critical understanding of the impact of disordered walking on Toby's sense of self.

Extracts from all participants are discussed and presented in this theme. Some extracts are discussed in more detail (e.g. Bill, Toby and Stella) and were selected because they were particularly powerful and articulate expressions of the theme, but extracts from the accounts of the other participants have also been used to illustrate the extent of the shared experience. This theme is divided into three sub-themes. The first is concerned with disrupted embodiment. The second discusses the impact this had on participants' sense of agency and cognition, and the third focusses on fatigue and cognitive overload.

## **6.2 Disrupted Embodiment: '*Everything is uncoordinated*' (Bill)**

Starting with Bill, he was asked to talk about what living with ataxia was like:

*'It's like kind of everything is uncoordinated. The frustration of a thing making perfect sense when you say it in your head, but by the time it emerges from your mouth it's kind of clumsy and awkward and ... the same with moving about. It's awkward, ungainly and painful and ... you can't do things quickly or arrogantly or whatever. Everything's kind of thick, knobbly and ungainly, uncoordinated, clumsy and just ... it's almost like being drunk all the time, except you aren't. [...] I've kind of lived with it for a long time really, over 20 years. So it's kind of difficult to think of what it was like not to have it. But the*

*other thing, when you see people kind of moving about you think 'How do they do that, isn't that clever'. You know stand up and you don't fall over and you move.'*

An empathic reading of this extract suggested, at first, that ataxia was experienced as primarily a physical phenomenon. Bill's account highlighted well known impairments associated with ataxia: uncoordinated movement; *'almost like being drunk all the time'* and dysarthria; *'by the time it emerges from your mouth it's kind of clumsy and awkward'*. The pauses in Bill's account seemed to signal his difficulty in explaining what it was like to live with this complex condition. In the end he seemed to run out of words, the use of *'just ...'* emphasised his struggle to explain. Finally he resorted to a "catch-all" description *'almost like being drunk all the time'* which fails to fully account for his experiences; *'except you aren't'*. The majority of participants (seven) used this phrase or similar at some point in their account to describe problems with balance, coordination and / or speech (Table 6.1). The phrase could be simply understood as a convenient short hand to describe symptoms that are almost beyond ordinary experience in a way that is familiar to others. However, the pause in Bill's account may also signal a reluctance to describe himself in these terms because of the discrediting undertones associated with being drunk.

**Table 6.1 Disrupted Embodiment: 'Like being drunk' (n = 7)**

Participant	Extract	Page: line number
Ted	<i>'Basically I feel like half-drunk most of the time'</i>	1:16
Harry	<i>'It's like being drunk all the time with no cause for being drunk'</i>	2:4
Bill	<i>'It's almost like being drunk all the time, except you aren't'</i>	4:34
Toby	<i>'It's like being permanently drunk'</i>	7:15
Jim	<i>'You look like you're drunk'</i>	14:12
Julia	<i>'I look and sound drunk'</i>	10:9
Graham	<i>'Looks like I'm completely drunk obviously'</i>	7:31

Staying with Bill and the phenomenological description, the above extract seemed to suggest that he had lost the sense of his comfortably familiar body; *'It's awkward, ungainly and painful', 'thick, knobbly'*. Bill no longer moved or experienced his body as he once did. Picturing Bill, it seemed that his speech as well as his movement were

somewhat inept. He lacked fluency (*'awkward, ungainly'*) and finesse (*'thick, knobbly'*). Stella also seemed to experience something similar:

*'I don't flow as normal people do, you know. There's a hesitancy there and when I'm going off the pavement I sort of make a big effort about it.'*

Although this extract depicts a certain tentativeness that is absent from Bill's account, Stella's *'big effort'* and her disrupted *'flow'* seem to echo Bill's sense of clumsiness and loss of arrogance. Both accounts hinted regretfully towards a time when moving about was effortless and unremarkable, and spoke of a once natural poise and bodily bearing that had been profoundly disturbed. For Bill and Stella, the experience of living with cerebellar ataxia seemed to have challenged what they had previously, perhaps subconsciously, understood about their body and its interaction with the world.

There was also a suggestion in these extracts of a loss of rapport between Bill and Stella and their surroundings; the world seemed to pose troubling obstacles that had to be carefully negotiated. Bill found his interactions in the world clumsy and awkward, and Stella rather than focussing on the activity that entailed getting off the kerb (e.g. going to the bank), had to think about coping with the kerb itself as a thing to be safely manoeuvred. The catch-all phrase *'like being drunk'* might therefore not only portray the way in which Bill's and Stella's natural poise and bearing was disturbed by ataxia, but might also capture the way in which the environment seemed to assail rather than accommodate their intentional projects.

For Bill in particular, there was an impression in his narrative that the physical experience of ataxia was of existential moment, it was *'looming large'*; what was once taken for granted is now problematic and occupies his attention. His once dependable body now betrays and constrains him and this robs him of certain existential possibilities. Bill compared himself and his own *'clumsy and awkward'* attempts at moving with the ease at which the people around him seemed to move. He watched other people in wonder; *'when you see people kind of moving about you think 'How do they do that, isn't that clever''*. His words resonate strongly with those of Toombs when describing her experiences of living with multiple sclerosis (1995:16):

*'I now perceive normal movement to be an extraordinary achievement. I catch myself watching students running across campus, or colleagues taking the stairs two-at-a-time, and I marvel at their effortless ability to do so.'*

With reference to Merleau-Ponty (1962 [1945]), Toombs (1995:16) explained this phenomenon in terms of an inability to 're-imagine' walking, and suggested that it signalled a long term transformation of bodily intentionality. According to Merleau-Ponty (1964:117), we understand what we have the potential to do by observing other people, because 'they are themes of possible activity for my own body'. Through comparison of herself with others, Toombs understood that her legs were 'no longer open to the possibility' of walking (1995:16). It seemed for Bill, as someone who walked by using a walking frame indoors and who used a wheelchair outside, that the possibility of walking was also closed off for him, the effortless action of others reminded him of what he no longer had the potential to do. Bill had lived with ataxia for many years and he was living with a comparable degree of physical limitation to that described by Toombs in her account. There was also a small hint of this phenomenon (i.e. comparing oneself with the effortless action of others) in Stella's account where she referred to not being able to 'flow' as 'normal people do'.

All the other participants (ten) talked about a qualitative change in their corporeal selves that resonated with Bill and Stella's experiences (Table 6.2 pp.115). These accounts spoke of an altered body that, like Bill's 'thick' and 'knobbly', perhaps signalled a change in the way the participants understood and identified with their body. The participants focussed on particular body parts which felt odd or distorted (Harry's 'rusty' hands, Stella's 'lead' legs and Toby's 'jelly' like knees). Joan and Susan described a sort of rigidity or stiffness which made them feel like a 'tin man', 'tin soldier' or 'matchstick man'. Toby explained that he felt 'wide at the top like a pivot', and like 'the top half wasn't connected to the bottom half'. In addition to the distorted shape, the reference to a pivot brings with it an impression of instability, as well as images of spinning and loss of control. For Toby the sense of bodily distortion was so profound that when he saw his physiotherapist he asked; 'can you give me something to do that'll tie my middle up?' Julia also described a disconcerting experience; 'my head was a fishbowl with the water slopping'. Again, there is the impression of loss of control; the water was spilling over the edge of the bowl, but also a disturbing sense of bodily transformation; Julia's head had become a fishbowl.

**Table 6.2 Qualitative Changes to the Corporeal Self (n = 12)**

Participant	Extract	Page: line number
Toby	<i>'Felt like my top half wasn't connected to my bottom half; felt like jelly'</i>	5:19
Joan	<i>'Like a tin soldier; the top doesn't belong to the bottom'</i>	Post interview note
Stella	<i>'This inability to walk straight and confidently'</i>	9:3
Susan	<i>'You just sort of feel like a match stick man or tin man'</i>	11:29
Bill	<i>'Everything's kind of thick, knobbly and ungainly'</i>	4:32
Hugh	<i>'Like Bambi, couldn't balance'</i>	1:25
Ted	<i>'You feel that you're going to fall over'</i>	1:33
Julia	<i>'My head was a fish bowl with the water slopping'</i>	14:18
Graham	<i>'I shake so much'</i>	11:23
Scott	<i>'My balance completely being disrupted'</i>	2:6
Jim	<i>'The biggest thing day to day is just balance and coordination, in that basically I've got none'</i>	14:5
Harry	<i>'They [hips and hands] feel rusty'</i>	14:3

Despite the unsettling and peculiar experiences described here, there was still a sense of body ownership in these accounts. The participants' bodies were experienced as different from their pre-ataxia selves; they were remarked upon and attended to however, the body still belonged to the participants albeit in a less familiar form. For Bill, however, it seemed in his experience of ataxia that nothing was untouched: *'everything's kind of thick, knobbly and ungainly, uncoordinated, clumsy'* (emphasis added). Bill might have been referring not only to his corporeal self here but also to his interactions in the world – all of his projects and plans had been disturbed and disrupted. This may reflect the length of time Bill had lived with ataxia and the extent of his disability.

At first the majority of participants (nine) found these changes to their normally taken for granted body quite baffling (Table 6.3 pp.116). The sense of bodily disorder and decomposition of movement felt strange and inexplicable; symptoms seemed to come out of the blue, *'for no apparent reason'* (Joan and Jim) which seemed either unaccountable, *'I thought I was going mad'* (Julia, and also Bill) or were attributed, at least at first, to something else; *'I thought it was to do with my feet'* (Susan). Most participants spoke about the unsettling experience of not being in full control of their actions with respect to their early experiences of ataxia. This is perhaps understandable

in that their new way of moving and being, even if they experienced only “mild” symptoms, would signify a considerable and enduring departure from what they had previously understood about their “normal” embodied activity.

**Table 6.3 Bodily Disruptions: Strange and Inexplicable (n = 9)**

Participant	Extract	Page: line number
Julia	<i>'I really thought I was going mad'</i>	14:21
Bill	<i>'What a relief [...] It's not madness'</i>	12:36
Stella	<i>'I thought well that's strange!'</i>	9:27
Joan	<i>'My legs just gave way for no apparent reason whatsoever'</i>	5:16
Hugh	<i>'My balance was gone!'</i>	2:17
Toby	<i>'Really strange'</i>	8:16
Jim	<i>'I'd just fall down for no apparent reason'</i>	12:32
Susan	<i>'I thought it was to do with my feet'</i>	4:23
Scott	<i>'It's quite strange'</i>	7:39

Over time, and following on from these initially quite bewildering experiences, it seemed that the participants learned to incorporate and manage their somewhat uncooperative and burdensome bodies within a process of on-going adjustment. This was perhaps exemplified by Harry, who had the most experience of adapting to life with ataxia; *'You evolve, you evolve to suit where you're at.'* However, even Ted, who had only been diagnosed for just over a year talked about learning to accommodate his unpredictable and unstable body;

*'It's still quite variable but generally I [...] ensure I've got my balance, rather than trying to do everything at one go [...] so you break down tasks and so you're slower in doing tasks.'*

Whilst Ted's example might seem to simply describe a common sense approach to coping with this newly unbalanced and uncoordinated self, all participants spoke in similar terms, of learning to live with their changing bodies (Table 6.4 pp.117). Importantly, it seemed that although the way they lived with their body had changed, and for some it was radically different from what they had previously known, their bodies still belonged to them. There was no sense in these accounts of bodily rejection or alienation

common to other accounts of the lived experience of similar neurological conditions (for example Toombs, 1993; Finlay, 2003b; Bramley and Eatough, 2005). The body, although strange and unpredictable, was still their ‘vehicle for being in the world’ (Merleau-Ponty, 2002 [1945]:94) and as such, and although often by extraordinary means, it had to be accommodated and managed in order to accomplish the wide range of activities and projects of interest to the participants.

**Table 6.4 Accommodating a Changed Corporeal Self (n = 12)**

Participant	Extract	Page: line number
Joan	<i>‘I’m learning to manage it better’</i>	3:29
Harry	<i>‘Whenever it gives you a problem find a way round it’</i>	3:8
Susan	<i>‘It’s just a matter of steadying myself and not going too fast’</i>	2:9
Stella	<i>‘I can lose my footing very easily. So I’ve just got to pace myself’</i>	13:2
Hugh	<i>‘I cut the grass [...] by holding onto the lawn mower [...] sort of like I know where the ground is, sort of acts like a counterbalance’</i>	10:32
Ted	<i>‘I do find that holding onto a pram does aid with my walking’</i>	8:22
Scott	<i>‘Always make sure there’s three points of contact anywhere around so I’m not going to go flying too fast’</i>	9:8
Bill	<i>‘When you do move, go and gather lots of things, to do three jobs at once’</i>	6:4
Julia	<i>‘I’ve had to learn to slow down. [...] I try not to do things impetuously’</i>	1:35
Toby	<i>‘Stand for maybe 30 seconds to let my muscles take the weight of my body and then go’</i>	10:34
Jim	<i>‘[Loss of balance] is something you can manage and something you can live with’</i>	14:7
Graham	<i>‘What I’m learning, if you like, is what I can do, what I need to do to try and stop me [...] hurting myself or other people’</i>	8:16

In summary, Bill’s and Stella’s accounts and the accompanying extracts from other participants began to convey the way in which bodily identity, this sense of having a physical self that is proper to one’s self and characteristically one’s own, might be disrupted by the experiential consequences of living with ataxia. The participants’ bodies certainly did not feel quite right and lacked the easy and skilful interaction with the world that, under normal circumstances, is taken for granted. However, there was no sense in these accounts that the body was ever anything other than “me”, a different sort of “me”

perhaps but nonetheless still owned and belonging to the participants. This next section further explores the phenomenon of identity and ownership of the body in ataxia with particular reference to the participants' sense of agency and cognition.

### **6.3 Disrupted Embodiment: Agency and Cognition**

Like Bill and Stella, the majority of participants (eight) described an effortful and uncoordinated way of moving that seemed to disrupt their sense of being the agent of their own actions (Table 6.5 pp. 119). Hugh and Joan for example both talked of '*staggering*' and '*lurching*' around, Graham described trying to avoid someone but ultimately overbalancing and giving them a '*bump*' and likewise Julia described herself as '*unpredictable*'. Scott recounted the following common occurrence which perhaps best captured this phenomenon:

*'When I'm walking towards people along a footpath and they're walking towards me but are obviously not going to hit me, I find subconsciously I go towards them. I don't know why. It's like you're trying to avoid hitting them but you're actually going towards them.'*

Here, it seems clear that Scott has a sense of ownership of his actions (he is the one moving and he is the author of his own movement) but he described a diminished sense of agency; he does not have a strong sense of being in control and he finds it difficult to understand or explain (*'I don't know why'*). The usual correspondence between intention and action seemed to have become unhinged in this example and this was echoed in other accounts (*'lurching'*, *'staggering'*, *'unpredictable'*). Put differently, Scott found that conscious effort (willing his body to avoid bumping into other pedestrians) was an inadequate substitute for loss of bodily control; *'subconsciously I go towards them'*. A straightforward activity usually involving little conscious attention seemed to have been transformed into a challenging ordeal. Similar to Bill and Stella, Scott's relationship with his surrounding environment has also perhaps changed; the coherence that usually typifies the relationship between a person and their environment seemed to be breaking down. Scott had started to see the world as a real threat to his intentional actions and projects, and spoke of weighing up whether or not to do certain activities in light of the perceived threat (*'you're assessing things which you can do or are going to be not so good for you'*), in Graham's words, to find out whether activities lie in his '*comfort zone*' or not.

**Table 6.5 Disrupted Sense of Agency (n = 8)**

Participant	Extract	Page: line number
Joan	<i>'My upper and lower body do not seem connected at all [...] I'm lurching around'</i>	2:41
Harry	<i>'You've got to say in your mind 'stop at that point, stop at that' if you leave it to your automatic stuff it would be [...] you know'</i>	9:23
Susan	<i>'You don't know where you're going to put your foot down and you need concentration'</i>	3:15
Stella	<i>'You can easily sort of veer to the side and bump into things'</i>	9:4
Graham	<i>'If I consciously have to step over [...] I tend to go sort of too far or not quite far enough'</i>	8:36
Scott	<i>'Consciously always trying to assess your feet, that you're not going to trip or kick into something'</i>	9:14
Julia	<i>'My mind will but my hands won't'</i>	7:5
Toby	<i>'You're trying to stop your body going this way and that way'</i>	7:24

Toby's description of his visual and balance impairments provided a further illustrative example of this loss of agency and altered relationship with the immediate environment. In this first extract, Toby recounts the following vivid experience: (there is also a hint of a stigma issue here which is discussed in detail in chapter 7)

*'And I could not ... particularly if people were behind me, walking behind me, that tends to make me worse ... but I was like a pinball, I was bounced off this wall, went to that wall, I could not walk in a straight line down that corridor [...] Really strange.'*

In this next extract Toby tried to explain what it was like to have his particular visual impairment:

*'It does effect your eyesight when you're walking ... I've said this to somebody before ... but you know a tank, say a Chieftain tank, you know the gun, they have the gyroscope so the tank can be going over all the terrain, you know up and down, but the gun stays constantly positioned on the target with the gyroscope, well that's what it used to be like when I was walking, that my eyes, looking ahead, I could be walking over terrain that was up, down, uneven, whatever, but my eyes would stay like the gun, constantly level. [...] But now it's like if you move over bumpy ground your eyes aren't locked, so your eyes are all over the place, yeah?'*

A close reading of Toby's account communicates firstly the sense of a body no longer fully under his control; the reference to the pinball is powerful here, signifying violent or turbulent changes in direction and a sense of disorder or powerlessness similar to Joan's *'haywire'* and balance going *'crazy'*, and Toby's own description of feeling like a *'pivot'*. The reference to the gyroscope and the Chieftain tank perhaps heightens the feeling of loss of control; something that was previously as dependable and as unassailable as a Chieftain tank, eyes locked and level, had now broken down, *'eyes all over the place'*.

Taking the analysis a bit further, it seems that the repetition of *'And I could not'*, *'I could not walk down that corridor'*, reveals the cognitive effort involved in trying to navigate the corridor. It seems that despite his best attempts Toby was unable to bring his walking back under control, a phenomenon he described as, *'Really strange'*. This phrase not only recaptures the unfamiliar body previously evident in Bill's and Stella's account: this is not Toby, but also the unnerving experience of not completely being in control despite his best mental or intellectual efforts. The powerlessness of the mind over the body is reinforced here, as it was in Scott's account (*'It's like you're trying to avoid hitting them but you're actually going towards them'*). It is therefore not surprising that dual tasking (e.g. walking and being aware of other pedestrians) is so difficult, an issue discussed in more depth later in this chapter.

Pushing the interpretation further and with reference to the cognitive effort, Toby's account could perhaps support Kirmayer's (1992:336) view that neurological dysfunction disrupts not only the *'content'* of thought but also its *'form'*. For Toby walking has become something that he has to think about (new content), but it is also an unfamiliar type of thinking (new form); Toby has to construct and control his walking through cognitive effort and he has to think about how his body negotiates space. Later in his account Toby talked of having to *'physically tense your muscles up in your mind'* which best captures this new way of thinking and new way of producing movement and which was evident in over half of the participants' accounts (Table 6.6 pp. 121). In the above example, Toby's account would suggest that his natural way of being in the world had been transformed, walking is now "thought about walking", and what he experiences is an artificial construction of walking built through conscious effort which would feel very strange.

**Table 6.6 New Ways of Thinking, New Ways of Moving (n = 7)**

Participant	Extract	Page: line number
Stella	<i>'The brain comes into this a lot really. And if I can master this you know ...'</i>	6:1
Harry	<i>'Teach your brain to take it over'</i>	9:29
Susan	<i>'The constant concentration of thinking where you're going to put your foot and where that puts your balance'</i>	3:18
Hugh	<i>'You're concentrating so much on your walking, like you can't enjoy your walk [...] if you try to look to the side or look back you lose your balance and fall over'</i>	19:30
Graham	<i>'You're desperate not to go to the left for example so you tend to overcompensate by going to the right, and that causes you know a different problem'</i>	7:45
Julia	<i>'My mind has to slow down to my body's pace'</i>	1:35
Toby	<i>'Physically tense up your muscles in your mind'</i>	7:25

What also emerged in these accounts was the concept of space as “thought about space”. Bill, Stella and the majority of the participants already hinted at this phenomenon when they referred to ataxia as *'like being drunk all the time'* (Harry), an experience that possibly pointed towards an understanding of the surrounding environment as hazardous, as something to be carefully negotiated. Toby's account of the corridor and awareness of other features of the environment strengthen the claim that ataxia, in addition to bringing the body into consciousness also brings “lived space” into the realm of what is thought about when thinking about moving. Graham's account lends further support to this claim. He was asked to talk about how ataxia had affected activities in his day to day life:

*'Well just how you get around, how you actually interact with that at home. You tend to make compromises in what you were doing, so for example getting out of bed. You know how far the wall is all of a sudden because quite often you stand up and you start falling over. So you grab hold of the wall or fall back on the bed or things like that. So that's part of what makes it a little bit difficult to go somewhere that's new, cos you don't know where you can put your hand down and that sort of thing. [...] An office environment it's fairly stable, you know, it doesn't tend to move about very much, so that's all right [...] but crossing the shop floor is horrendous, so I don't do that any more.'*

In this extract Graham is acutely aware of the layout of space at home and at work. He has identified what for him are stable and unstable environments and steers clear of anything that is too unpredictable where he might put himself and others at risk. Visualising Graham at work and at home it seems as if he moves almost as if he is blind, groping for hand holds that will help him move safely through space, critically aware that any misstep could lead to a fall. There is a striking similarity here with Sack's (1985) account of Christina, a woman with a rare and severe proprioceptive impairment which resulted in a type of sensory ataxia. She explained her lack of proprioception as follows:

‘This ‘proprioception’ is like the eyes of the body, the way the body sees itself. And if it goes, as it’s gone with me, *it’s like the body’s blind*. My body can’t see if it’s lost its eyes, right?’ (Sacks, 1985:46 original emphasis)

Graham spoke mostly about experiences that would suggest that he had significantly impaired proprioception and this is perhaps why there is such resonance between these two accounts. Graham described interacting with space as if he was blind, more accurately perhaps, as if his unpredictable body was sightless (*‘I tend to go too far or not quite far enough’*), and as a result space emerged as something that required an unusual amount of attention, as an entity to take account of and contend with in everyday life.

These accounts lend support to the earlier understanding of ataxia as a phenomenon that disrupts the sense of self. Not only is there a diminished sense of having a body that is comfortably “me” but also, a sense of a body that can no longer be fully controlled by “me”. In this sense, the participants’ experiences revealed an ambiguous relationship between the mind and the body in ataxia. The accounts spoke of a heightened awareness of the body as a corporeal entity that operated in the world in new and somewhat extraordinary ways whilst still being “me”. At the same time, participants referred to the mind and consciousness as if it was something that might have power over the body but in their experience it was able to assume very little control. Furthermore, the emergence of the body brought with it the emergence of space as “thought about space”, an awareness of the environment as conditional, capable of derailing or at least constraining valued projects and tasks.

So what seemed to surface in these accounts was not only a heightened awareness of the corporeal body but also an emergence of the conscious mind as a somewhat limited means of controlling the body. This loss of agency did not simply involve the body but also the way in which the body negotiated the environment. There was an awareness of

space as potentially hostile to participants' on-going activities in the world and an understanding that negotiating even the most familiar of environments required an inordinate amount of attention. However, rather than rejecting the body it seems that the participants used what resources were available to them (effort, determination, re-learning, re-thinking) to accommodate (make room for, as well as to adapt, adjust and assist) their body and, by doing so, continued to involve themselves in the world, as best they could.

#### **6.4 Fatigue and Cognitive Overload: Disturbing Consequences of Disrupted Embodiment**

Participants' attempts to harness cognitive resources to try to achieve a sense of corporeal mastery were hugely effortful. The attentional demands which were required to help deal with this bodily disruption, having to concentrate *'twice as hard'* on everyday tasks (Harry), were extremely fatiguing;

*'That's one thing, you lose your automatic bits ... it's fine if you teach your brain to take it over. But again, you'll wear yourself out really quickly'* (Harry).

Here, Harry clearly describes how he has lost the subconscious control of movement, his *'automatic bits'*. Harry has tried to train himself to consciously take control of what would normally be constituted subconsciously and automatically, but he is rapidly fatigued by the effort involved, limiting the extent to which he can pursue his projects and tasks; *'You burn out quicker, have a small energy band.'* Similar feelings of overwhelming fatigue were recounted by the majority of participants (nine), see Table 6.7 (pp. 124).

**Table 6.7 Overwhelming Fatigue (n = 9)**

Participant	Extract	Page: line number
Joan	<i>'Exhaustion beyond normal tiredness'</i>	5:8
Harry	<i>'You burn out quicker, you have a small energy band'</i>	2:12
Susan	<i>'I'm tired all the time it's just a way of life'</i>	4:14
Hugh	<i>'I get very tired [...] If I do a length or two [swimming] that's me shattered'</i>	12:8
Ted	<i>'When you're tired you end up making problems [...] it's just a continual circle'</i>	4:6
Graham	<i>'If I'm tired one day, I'll be tired for several days afterwards'</i>	2:28
Julia	<i>'I went to bed and almost for a day and a half [...] because I knew I couldn't go on at that rate'</i>	8:19
Scott	<i>'You are fairly knackered, you're debilitated in various forms'</i>	5:19
Toby	<i>'It just takes that much out of you physically and mentally, just totally shot'</i>	7:18

Most participants, except Jim and Stella, spoke freely of their experiences of fatigue and offered extensive explanations of what this sort of fatigue was like, stressing a profound loss of energy; *'It's like extreme fatigue, yeah, not just tired'*, *'I liken it to a battery – I start going down'*, *'totally shot'* (Toby). However, in contrast to most participants, Jim and Stella only talked about fatigue when prompted by the researcher. Stella explained her fatigue in terms of ageing;

*'I get tired now more than I used to when I was younger, but I think that's the ageing thing really more than anything. If I have my granddaughter for more than a few hours that kills me. [...] She's very lively, you know, on the go all the time, oh dear me ... and I'm glad to hand her back. But no, I wouldn't say so, I wouldn't say I tired very easily. I've got a lot of stamina really and I suppose it's built up over the years.'*

This way of explaining her symptoms might be an attribution issue, a way of normalising. Stella was very fit and active previously (*'because I used to be so active I find it very hard'*), she may find fatigue a slightly discrediting experience that is more acceptable to her framed within the normal tiredness of ageing and looking after grandchildren. However, she simply might not experience the same kind of fatigue as other participants. Similar issues were raised by Jim and Graham. Jim seemed to reluctantly acknowledge that his fatigue might be to do with ataxia but he preferred to frame it within the more normal bounds of overwork and a busy lifestyle: (as with Toby's earlier

extract, there is also a hint of a stigma issue here which is discussed in detail in chapter 7)

*'But yeah, it's difficult, you do feel tired. But part of you thinks well it's work, it's age ... it's everything else you're trying to cope with. And trying to say yes I've got ataxia, that is a prime concern ... or a prime cause ... it's difficult.'*

Graham also placed feeling 'tired' and 'listless' within a narrative of long hours working with computers and he was not sure whether this was 'ordinary or whether that's, you know, brought on by the ataxia'.

There was certainly some unwillingness to admit the impact of fatigue in these three accounts. As with Stella, reframing might be a means of normalising, keeping what could be a significant and troubling symptom, something that could get worse, away from being associated with ataxia. Kept in the world of work and grandchildren fatigue is in a more manageable place, where in theory it could be controlled, for example if less time was spent at work or with the grandchildren. For the majority of participants however, fatigue was experienced as part and parcel of living with ataxia and was intertwined with trying to manage and attend to the associated physical symptoms; collectively these efforts formed the backdrop against which life had to be organised, adjusted and at times constrained.

In addition to fatigue, two participants found that having to focus on tasks and activities that had previously been managed at an automatic level involved a heightened awareness of cognitive processes and fragile cognitive capacities. There were hints of this phenomenon in three other accounts (Table 6.8 pp. 127) but Julia and Toby perhaps captured the experience of cognitive overload most clearly. Firstly Toby:

*'I don't seem to be able to handle inputs ... like when I go swimming I have to pick a relatively quiet time because I can't handle all these audio inputs, visual inputs, trying to remember how many lengths I've done, trying to coordinate my hands and legs and breathing, and it's just too much, it's like the computer crashes, yeah?'*

Having to concentrate on activities that would usually be managed subconsciously (breathing, coordinating arm and leg movements), Toby found that he was unable to screen out stimuli that would normally be on the periphery of his awareness. Audio and visual inputs somehow find their way into consciousness and distract Toby from his efforts to co-ordinate his swim stroke and remember the number of completed lengths. It seems that, for Toby, the cognitive effort required to manage previously automatic

activity has, at the same time, reduced his ability to filter out other, normally innocuous, stimuli. Both important and insignificant stimuli seem to draw his attention and eventually overwhelm him (*'the computer crashes'*). Julia recounted a similar experience:

*'... I guess one thing that I can't plan is that sudden noises make me jump, and if I'm not in a position where I can hold onto something I will fall. So if a car toots ...'*

For Julia, the meaning and significance of the sound of a car horn has changed. Instead of understanding it as a signal that something might be happening in the road, it now carries a direct and personal significance, meaning "Hold on!" or "Keep steady!" A car beeping its horn is sufficient to disrupt Julia's ability to concentrate on staying upright. Although startling, it would be unusual to fall over on hearing a car horn, however, if Julia has all her attention trained on standing up then one additional input may do just enough, as with Toby, to draw her attention away from keeping her balance and cause her to fall.

Julia's account of the car horn suggested that carefully constructed physical competencies can, at any moment, be completely destroyed by the smallest distraction or oversight. For Julia this means that she has to carefully monitor even the most basic activities. In this next extract Julia talked about making a cup of tea:

*'...if I make a drink I put the cup in the sink or on the draining board, because I don't want hot things being loose. And I no longer do two things at once. My mind will but my hands won't. [...] So I have to not get frustrated but try and control what I am doing with my movements and things. Mentally instead of automatically.'*

Julia perhaps best captures the hyper-vigilance that seems to accompany coping with ataxia in everyday life. She can no longer assume that her hands will automatically carry out her planned activity. Julia's hands are now part of her conscious awareness and require her full attention, so much so that she is no longer able to manage doing more than one task at a time. There is also a hint here of the vigilance required not only in the execution of a task in real time but also the planning that needs to go on ahead of time, Julia continues:

*'My mind has had to slow down to my body's pace, that I now ... I try not to do things impetuously, I try to stop before I turn, just plan ahead really.'*

For Julia, routine tasks like washing up and crossing a room require her full attention and forward planning, even the sound of the door bell can disrupt her carefully rehearsed strategies. Like Toby, Julia describes a clear sense of awareness of cognitive process and the extent to which her cognitive capacity is limited by having to attend to her corporeal self.

**Table 6.8 Cognitive Overload (n = 5)**

Participant	Extract	Page: line number
Hugh	<i>'By concentrating on the stick you can't think of two things. So you're trying to walk at the same time [...] you can't do it'</i>	11:13
Hugh	<i>'I can't put a camera around my neck, the swaying ... my brain's reacting to it and I end up falling over'</i>	11:25
Toby	<i>'... particularly if people were behind me, walking behind me, that tends to make me worse'</i>	8:10
Susan	<i>'I can't think of doing things like carrying and walking at the same time'</i>	7:3
Julia	<i>'It's more and more activity and noise around me [...] which I find tiring'</i>	8:9
Scott	<i>'When I'm walking towards people along a footpath and they're walking towards me but are obviously not going to hit me, I find subconsciously I go towards them'</i>	7:34

In summary, this section points towards an understanding of ataxia as a phenomenon that changes the content and form of thought, perhaps exemplified by Harry's attempt to *'teach your brain to take it over'* and Toby's experience of having to *'physically tense your muscles up in your mind'*. Living with ataxia seems to entail new ways of thinking; harnessing cognitive effort not simply to achieve some semblance of "normal" movement but also as a means of recovering a sense of self through reclaiming bodily agency. However, fatigue and cognitive overload also seem to be common and disruptive corollaries of this new and seemingly permanent shift in the participants' way of thinking and being, and in themselves pose further challenges to contend with and manage.

Concrete experience of the contingency of embodiment and the conditions that this particular ataxic embodiment placed on intentional activity seemed to not only project the body into consciousness but also to call attention to the mind as a possible resource for controlling the body. However, instead of the mind taking over from the body, participants described new ways of moving, doing and coping with the world in which the

mind and body worked together as optimally as possible. In this sense neither the mind nor the body had primacy; both were qualified by ataxia.

## **6.5 Summary**

Participants' accounts of the physical effects of ataxia were striking and provided a nuanced understanding of the embodied experience of living with ataxia. Bill's account offered a way into understanding the experience of ataxia as more than just a collection of interacting physical impairments. A close examination of Bill's and of the other participants' accounts shed light on the phenomenon of ataxia and helped reveal the body-as-lived. For the majority of participants, the embodied experience of ataxia was one of a once familiar body that had become (to a greater or lesser extent) uncontrollable, unreliable and unpredictable. All participants were engaged in a process of trying to manage and accommodate their disordered body and, as part of this process, their body emerged into consciousness as something to be thought about and taken into account for even the smallest and most automatic of tasks. For most, unless carefully managed, this effort drained cognitive resources to the point of exhaustion and compromised participation in valued activities.

An initial focus on the bodily experience of living with ataxia led to new ways of understanding participants' symptoms and impairments but also, acting heuristically, provided a way into understanding other aspects of the participants' lived experience that had been fundamentally altered through living with ataxia. Living with ataxia seemed to entail a heightened awareness of not only the body but also the production of movement, the mind and the immediate environment (kerbs, corridors, and people) that seemed very different from "normal" intentional activity. Bodily changes interacted with and modified the participants' understanding of their bodily identity, and their understanding of lived space. These concepts; corporeality and spatiality, have been identified as fundamental structures of the lifeworld (Merleau-Ponty, 2002 [1945]; van Manen, 1998; Ashworth, 2003; Langdrige, 2007) and are common themes in phenomenological enquiry. Their presence in this analysis is therefore not unexpected but these themes emerged directly from the participants' narratives and were not used a priori to direct or influence the analysis.

## 6.6 Discussion

### 6.6.1 The Emergence of the Body in Ataxia

The participants in this study seem to have lost the sense of their body as ‘experientially absent’ (Gallagher, 2005:147). Instead of body parts being known only through their role in intentional activity, peripheral to consciousness (e.g. legs for walking across a room, arms for reaching for a glass), body parts emerged into consciousness in a modified and disintegrated way (*‘jelly’* like knees, *‘rusty’* hands, *‘lead’* legs, *‘eyes all over the place’*); as out of shape (*‘thick, knobbly’*) and distorted (*‘like a pivot’*). The body was clearly identified in the participants’ accounts in corporeal form, often understood or described in terms of its instrumentality. Joan and Susan for example drew on mechanistic descriptions (*‘match stick man’*, *‘tin soldier’*) which conveyed the body as object and in particular as machine. Joan also described herself in terms of a faulty machine: *‘I do find that I malfunction to a very large extent’*, and there are obvious parallels here with Toby’s comparison to a Chieftain tank. So rather than being surpassed or silent (Sartre, 2003 [1943]), the body, in these accounts, took on a new kind of presence and encroached upon conscious awareness.

The participants’ accounts resonate with the perspectives of Gallagher (1986) and Toussaint (1976) who suggested that the body becomes object-like when it is encountered as an obstacle which frustrates one’s intentional projects:

‘On all such occasions when my body lacks the dexterity to execute my intentions, it gets in the way. When my body becomes an obstacle to overcome, rather than the smooth embodiment of my intentionality, we have an instance of what I prefer to call the phenomenon of the body or the body as object.’ (Toussaint, 1976:176)

Under normal circumstances, intentionality and physical capability are in “lock-step”, the body is naturally and automatically invested in intentional activity without conscious awareness. According to Marcel (1951) disrupted embodiment, creates a gap between intention and action, and rather than instantaneously and skilfully fitting together, the harmonious arrangement between the body and intentionality breaks down and it is at this point, as it was for Joan and Toby and the majority of the participants in the study, that the instrumentality of the body emerges.

This emergence of the body in consciousness is not unique to the lived experience of cerebellar ataxia, and has been described in the literature with reference to the lived

experience of other neurological conditions such as sensory ataxia (Sacks, 1985; Gallagher, 2005); multiple sclerosis (Toombs, 1993; Finlay, 2003b); Parkinson's disease (Habermann, 1996; Fox, 2003; Bramley and Eatough, 2005; Sunvisson et al. 2009) and brain injury (Howes et al. 2005). However, the way in which the body emerged in the accounts of participants in this study seemed to differ from some of the literature cited above and in other published work concerned with understanding human embodiment and the body in illness (Sartre, 2003 [1943]; Zaner, 1981; Leder, 1990).

### **6.6.2 The Emergence of the Body as Object and Alien in Illness**

Toombs (1988; 1992; 1993; 1995; 2001) wrote extensively about the body in illness, specifically in terms of living with a progressive neurological condition. By drawing on the work of Sartre (2003 [1943]) and Zaner (1981), and through exploring her own experiences of living with multiple sclerosis, Toombs (1993:70) claimed that the body is objectified in illness and '*necessarily* accompanied by feelings of both alienation from and unwilling identification with the body' (emphasis added). This conceptualisation of the body resonates with the accounts of the participants in this study in terms of making sense of the disrupted body as object and dysfunctional machine. However, it seems to diverge somewhat from their particular experiences. The body in ataxia did not seem to be experienced as radically alien to the self nor did the participants seem to lack empathy with their embodied selves as suggested by Toombs and her 'unwilling identification' with her body.

Zaner's (1981:54) original conceptualisation of the body as 'alien presence' is part of a larger body of work that attempted to come to an understanding of the body in human experience. Zaner emphasised the experience of the "otherness" of one's own body as an inherent part of normal human embodiment. Zaner explained that whilst the body in ordinary experience is 'inescapably implicating, hidden and chilling' it is simultaneously 'familiar, intimate, enabling and accustomed' (1981:54). The body as it is usually lived is at the same time familiar and strange; intimate and alien; mine yet other, Zaner thus states; 'we are continually flirting with paradoxical expressions in an effort to tell truly the character of embodiment [...] No sooner does one feel tempted to say 'I *am* my body' than one *realizes* that 'I am yet *not* my body'" (1981:54, original emphasis). In this way Zaner (1981) goes beyond Sartre's phenomenology of the body (2003 [1943]:355) by more clearly identifying the ambiguity of the body and, in his view, the fundamental alien presence of the body in everyday experience.

Toombs (1992; 1993) took Zaner's conceptualisation of the lived body in health and transposed it to help make sense of the situation of the body in illness. By exploring her own experience of living with MS, Toombs (1993, 2001) suggested that in illness more than in health, the unknown processes and events of the alien body are explicitly exposed. Toombs' view has some resonance with Leder's (1990) work which was concerned with the experience of pain and other states such as pregnancy that alter the ways in which the body functions. Leder (1990) proposed that, under normal circumstances the body is 'recessive' (1990:36) but the body in pain emerges as 'alien presence' (1990:73, 77, 91) in a bad or ill way, hence '*dys*-appearance', and as such the body is experienced as 'away, apart from the self' (1990:87). Similar to Zaner's conception of the body, for Leder the body in health is experienced as 'alien-as-forgotten' and in illness as a 'sharp and searing presence threatening the self' (1990:91), suggesting perhaps alien-as-remembered. So although there is a degree of conceptual consensus here about the way in which the body is lived in health and illness, the empirical evidence for experiencing the body as alien might bear further scrutiny. Zaner (1981) for example restricted his comments to the way in which the body is experienced in health, and Leder (1990) focussed primarily on the body in pain. However, Toombs (1992; 1993) drew on her own experience of living with MS for many years and in her experience it is clear that she felt alienated from her body. There may be particular reasons located in the lived experience of MS as to why this might be the case.

Multiple sclerosis often entails sudden relapses which may lead to significant functional losses and profound sensory changes (Compston et al. 2005). These relapses are unpredictable, the 'Sword of Damocles' constantly threatening an inevitable fate (Finlay, 2003b:165). For Toombs (1992), the expectation of bodily disruption became a normal part of her daily life; she believed that she lived with a body that would ultimately betray her, a fate from which she could not flee. In her experience of MS, the sense of bodily alienation was particularly resonant in the numerous ways in which her body let her down and in the humiliating way in which bladder and bowel dysfunction further alienated her body from her sense of self. In this way it is possible to see, as suggested here by Toombs but also by Finlay (2003b), how the body in MS could be understood as seemingly alien, as a malevolent force which may, at some point of its own making, take over the body completely.

Cerebellar ataxia, in contrast to MS, is not characterised by sudden and potentially devastating relapses that are typical of the most common form of MS. The body in ataxia seems to be experienced primarily as an encumbrance; it is awkward, ungainly

and frustrates intentional activities. It is in itself incredibly wearing but nonetheless it still belongs to the self. There was little if any sense in participants' accounts that their bodies carried the same threat or such intense feelings of alienation as described by Toombs (1988; 1992; 1993) or Finlay (2003b).

In Finlay's (2003b) idiographic account of the early experience of being diagnosed with MS, she described the following experience where the participant, Ann, seemed to have lost all proprioception in her right arm; 'It had a life of its own ... And it just used to fall off things ... it would just suddenly come up like this and it was very strange' (Finlay, 2003b:163). The objectification of the arm here is clear ('it'), but what seems important to the interpreted account is the completely involuntary nature of the moving arm, it seems to move by itself. In this sense (and in contrast to the participants in the present study) Ann seems to have lost all sense of agency *and* ownership. Finlay (2003b:167) interpreted this extract as being indicative of bodily alienation: 'It feels out of her control, as if an alien infiltration has arbitrarily taken over'.

Gallagher (2005) documented the experiences of Ian who had a rare and severe proprioceptive impairment which resulted in a type of sensory ataxia (not the kind of ataxia as experienced by the participants in this study). Ian had no proprioceptive sense of posture or of limb position, resulting in a complete loss of postural and motor control. In the acute stages of his illness he was unable to compensate for the deficit by using vision, and consequently 'the felt sense of his own body as *his own* and as under his control had disappeared' (Gallagher, 2005:51, original emphasis). Gallagher (2005:56) explained that Ian experienced a 'loss of embodiment' or 'alienation' from his body in these early days and weeks which were linked to his sense of ownership of his body. As he learned to use vision to compensate for the proprioceptive loss and to regain bodily control, his sense of ownership of his body returned and the sense of alienation diminished.

What seems important to the sense of alienation identified in these two accounts is the total loss of control, perhaps best expressed by Marcel:

'If I lose *all* control of my body due to some illness or injury, it would cease to be my body and in a sense it would be meaningful to say 'I am no longer myself'' (Marcel, 1950:14, emphasis added).

In the above accounts, where there is total loss of control in which the body or a particular body part seems to take on a life of its own, or is infiltrated by something that

seems other than the self, the understanding of the body as alien seems to be borne out and it emerges as a very real and disturbing part of living with a particular illness or condition. However, participants in the present study did not experience their bodies or even part of their bodies moving completely involuntarily, action was imperfectly executed but was nonetheless always part of a willed, voluntary movement. Therefore in comparison to the cases described by Gallagher (2005) and Finlay (2003b), participants in the present study seemed to retain their sense of bodily ownership and although disrupted, the sense of agency, of being in control of their limbs, was never totally destroyed.

In an unusual example of what is more commonly experienced as alien hand syndrome (Brainin et al. 2007), Sacks (1985:55) described a phenomenon where a man who seemed to have suffered a stroke fell out of bed because he believed that his leg was a 'counterfeit' of his own leg. He tried to throw the imposter leg out of bed but as it was in fact his own leg he obviously followed it and fell out of bed with it. Still a rare phenomenon, this syndrome occurs following a particular type of stroke that involves a disruption of cortico-subcortical circuits whereby limb movement becomes detached from motor planning and execution (Brainin et al. 2007). Much like the previous examples concerned with proprioceptive loss, the involved limb seems to take on a life of its own. Here the sense of belonging is completely disrupted and it can be seen how in this instance the body may be understood as alien to the self. However, this is not the kind of phenomenon that the participants in this study described or experienced.

In a single case account of the lived experience of Parkinson's disease (PD), Bramley and Eatough (2005) also identified an example of the phenomenon of the body as alien. However, this only occurred under particular circumstances when the drugs used to control rigidity and bradykinesia took effect, what are known as "on" periods. The result was an artificially produced and excessive amount of movement described as 'extreme involuntary movement (facial and torso twisting and limb jerking)' (2005:227). The similarity here with the previous accounts is that this movement took place involuntarily. It was as if the body had a life of its own, synthetically instigated by the drugs, something outside and alien to the self.

In contrast, in Michael J Fox's account of his life with PD (Fox, 2003), he described his off periods (when the medication was not working and the symptoms of PD were most profound) as a time when the disease had 'complete authority over my physical being.' He continued 'I am utterly in its possession' (2003:256). It is in this instance that his experience of his bodily self could be interpreted and understood as alien, overrun and

invaded by PD. When the drugs take effect, the freedom of movement he reclaimed, albeit accompanied by involuntary spasms and tics similar to that described by Bramley and Eatough (2005), are entirely welcomed as his 'body's way of celebrating the reunion of mind and motion' (Fox, 2003:259-260). In a further study, Sunvisson et al (2009) identified ways in which people with PD learned to accommodate both the off and the on periods. For example, Mary learned to adapt to 'what she felt her body wanted', she followed, and almost seemed to embrace, the vagaries of whichever embodied state she experienced at the time, whether 'on' or 'off' (Sunvisson et al. 2009:245).

These accounts lend support to the idea that the body is not inevitably experienced as alien as a consequence of living with a neurological condition. Where a limb or the body seems to take on a life of its own (e.g. where proprioception is particularly impaired or in certain kinds of stroke) or where the body seems to be especially under threat or humiliated by a particular disease (e.g. in MS) there may be a stronger tendency towards alienation. However, for the most part, it seems that it is the particular circumstances of individuals that shape how the body is experienced and understood as part of living with a neurological condition.

There is no doubt that illness engenders a form of embodiment that differs from that of everyday experience. However, the accounts of participants in this study seem to support the view that rather than necessarily posing a threat to the lived body or objectifying it, illness 'qualifies' human embodiment (Rothfield, 2008:222). In other words, illness brings about a certain kind of embodiment, but not a form of embodiment where the body is inevitably understood as object (Sartre, 2003 [1943]; Toombs, 1993), alien (Zaner, 1981; Toombs, 1993) or dys-appeared (Leder, 1990). Rather, each condition, as Leder (1990:81) also explained, 'is characterised by its idiosyncratic motifs of disruption'.

The type of embodiment described by Rothfield (2008) seems to capture Merleau-Ponty's (2002 [1945]) perspective of the body and how it is lived in ordinary experience. Illness, and ataxia in particular, brings with it a fundamentally altered way of being-in-the-world which calls for new ways of doing things that may be radically different to "normal". It is this understanding of the body in illness, an understanding that resists absolutes and dichotomous categorisations that seems to resonate most strongly with the accounts of the participants in this study. This way of understanding the body and the body in illness underlines the importance of careful and detailed enquiry into a wide range of conditions and illnesses, including progressive cerebellar ataxia. Slotting what has been traditionally understood about the experience of a particular condition (e.g.

progressive cerebellar ataxia) alongside another similarly labelled condition (e.g. MS) risks representing one experience as another, and may lead to false assumptions and misunderstandings.

### **6.6.3 The Emergence of the Mind in Ataxia**

#### **6.6.3.1 Movement as “Thought About” Movement**

The lived experience of cerebellar ataxia entailed thinking about movement in a way that was very different to the participants’ pre-reflective and skilful ways of moving remembered from a time when ataxia had little or no impact on their lives. Unlike Merleau-Ponty’s description of a body that is always with us, always in the right place and ahead of our conscious thoughts (2002 [1945]:108), it seems that participants in this study had to look out for their body, make sure it was with them and lead it towards the movement’s completion. Stella provided a further example of this phenomenon:

*‘If I try to rush, that’s when it’s difficult for me. Because my limbs won’t move fast enough for my head, my head’s going through the door but my limbs ... [...] won’t move as fast.’*

Normally, action is faster than the sort of consciousness that would be required to monitor action; in Gallagher’s terms (2005:237), action happens ‘before you know it’. However, Stella understands that even for ordinary, everyday activity, because her body no longer anticipates her actions, she has to slow her movements down to “thinking speed” in order to safely negotiate her environment. When she is in a hurry she almost forgets that she needs to consciously think about moving. In her ‘head’ she is already through the door but in reality she knows that she has to go back to retrieve her body and attend to it so that she can safely negotiate the door without falling. Stella’s body no longer “thinks” for itself as it would have done before she had ataxia.

Merleau-Ponty (2002 [1945]:159) claimed, with reference to motility, that ‘Consciousness is in the first place not a matter of an ‘I think that’ but of an ‘I can’.’ This claim is central to Merleau-Ponty’s philosophy and has a distinct relevance to the interpretation of the accounts of participants in this study. Merleau-Ponty does not deny the mind; rather he enhances the understanding of the body by also allowing it to think (Reynolds, 2005). By accommodating itself with the least amount of effort to its environment, the body seeks equilibrium (Merleau-Ponty, 2002 [1945]:177) and thus manages to avoid the wild fluctuations that would disturb bodily stability and necessitate conscious monitoring and control (Reynolds, 2005). Disruption of the subconscious

habits underpinning “normal” movement brings the body into consciousness as something to be dealt with and thought about. However, ‘bodily intelligence’, as the name would suggest, is not held in the mind, rather, as Merleau-Ponty explains with reference to typing, it is ‘in the hands’ (2002 [1945]:166). It is only through bodily effort and not through detached cognitive effort that we “know” i.e. that we are capable of skilful coping. In other words, ‘[w]e have a *feel* for the kinds of balance and posture that afford us a correct and proper view of the world, and that feel is neither the buzz and hum of sensation nor the rationality of deliberate thought’ (Carman, 2008:110-111, original emphasis). Intentional activity brought about by an “I think” therefore is experienced as a very different way of being when compared to a fully functioning body sustained by body-habits.

Similar to the participants’ accounts in this study, it seems that people living with other neurological conditions such as Parkinson’s disease (Habermann, 1996; Sunvisson et al. 2009) and conditions such as dyspraxia (Blijlevens et al. 2009) and visuospatial agnosia (Lampinen and Tham, 2003) also have to think about moving in a way that is unfamiliar to how they moved previously. The phenomenon of having to think about movement then is not uncommon for people living with neurological conditions. However, the way in which the movement is thought about and the sense people make of this seems to differ depending on the particular condition and its specific effects on motor control. This study shows something new in this respect. The participants in this study have added new emphases and have helped to reveal subtle differences in the interactions of the mind and body in illness. For example, adults with dyspraxia seem to find the particular ways in which their body lets them down as an embarrassment, as a failure of the self (Blijlevens et al. 2009). Not simply *unable* to accomplish activities learned in childhood such as dressing, but seemingly to have *forgotten how*, implicated the body and the self as useless. In ways similar to the experience of the body in ataxia, people with Parkinson’s disease also seemed to understand their bodies as out of control and uncooperative (Habermann, 1996). However, the lived experience of Parkinson’s disease is also complicated by the effects of the drugs and the on and off periods which are understood in very different ways depending on individual circumstances (Sunvisson et al. 2009). People with visuospatial agnosia found that their sense of self was in many ways deeply disrupted because previously automatic and unthought about actions had been rendered impossible or required exceptional cognitive effort (Lampinen and Tham, 2003).

Living with progressive cerebellar ataxia, as recounted by the participants in this study, involved a disruption of skilful coping that is particular to ataxic embodiment. There are elements of this disrupted motility that are shared with other neurological conditions particularly with respect to loss of control. However, this study reveals that it is the loss of the optimal bodily attitudes that normally provide the grip on the world and from which experience is integrated and secured (Carman, 2008) that seems particular to life with ataxia. In ataxia, the mutual dependence or empathy between self and world seems to break down as the ability to anticipate and incorporate the environment in action fails. As a result, the world becomes observed in a newly conscious way, kerbs, doors, walls and passersby hold the attention, attempts are made to bring the body under control, and effort is expended in trying to maintain equilibrium. The world seems to pose risks and dangers that can only be avoided through an exhausting kind of vigilance that for some leaves little room to cope with other tasks and distractions.

#### **6.6.3.2 Cognitive Overload and Fatigue**

Four participants described experiences where they became aware of cognitive overload during everyday activities. Although this phenomenon was only identified in these four accounts it seemed to be particularly meaningful for the participants who described it. Toby, for example, had to make sure that he minimised distractions whilst he was carrying out complex tasks like swimming, and Julia had to be aware of potential risks to her balance caused by unanticipated distractions which threatened her attentional capacity. What seemed to be described in these accounts were difficulties associated with dual-tasking and managing finite attentional resources.

Cognitive problems associated with cerebellar ataxia form the basis for much controversial discussion (Schmahmann, 1998, 2010; Schmahmann and Caplan, 2006; Bellebaum and Daum, 2007; Haarmeier and Thier, 2007). Whilst some authors conclude that there is at best only weak evidence to support a role for the cerebellum in cognition (Glickstein and Doron, 2008) or attention (Haarmeier and Thier, 2007), others contend that the cerebellum has an established role in cognitive function (Schmahmann, 1998; 2010; Schmahmann and Caplan, 2006). However, the most appropriate methodology for discerning valid conclusions about the role of the cerebellum in cognition is yet to be agreed and remains a matter of debate (Bellebaum and Daum, 2007; Haarmeier and Thier, 2007; Schmahmann and Caplan, 2006; Timmann and Daum, 2007).

Schmahmann is perhaps the most prominent of those who support a role for the cerebellum in cognition (Schmahmann, 1998, 2010; Schmahmann and Caplan, 2006).

By drawing on case study and laboratory based work from people with a wide range of cerebellar dysfunction Schmahmann suggested that the cerebellum not only acts to optimise motor control but optimises performance according to context across a number of behavioural domains. He suggested specifically that cerebellar dysfunction could be implicated in problems with mental flexibility, multitasking, visuospatial organisation, linguistic processing and mood (Schmahmann and Caplan, 2006). Whilst his views remain somewhat controversial and the anatomical details and methodological challenges still need to be addressed, Timmann and Daum (2007) suggested that there does seem to be converging evidence in support of cerebellar involvement in cognitive processing, chiefly in terms of verbal working memory which may have some bearing on performance in other complex cognitive tasks.

It is tempting to suggest that Schmahmann's understanding of the role of the cerebellum in executive function may have some bearing on the experiences reported by Toby and Julia, i.e. that cerebellar ataxia impairs the cognitive function of the cerebellum as well as its role in motor control. On the other hand, dysfunction of the cerebellum may simply result in poor execution of the cerebellum's role in motor control so much so that the cerebral cortex is required to provide oversight to motor functions that would normally be the responsibility of the cerebellum. The cerebellum specialises in controlling automatic movements that involve multiple joints and muscles in such numbers that it is impossible to consciously think about each element and its contribution to movement control (Thatch, 2007). Failure of the cerebellum would simply ask more of the cerebrum than it is capable of taking on at a conscious level, and might therefore result in the cognitive overload experienced by the participants in this study.

Toby and Julia's experiences lend some real world weight to theories that have been principally investigated in the laboratory and clinic and which might benefit from further phenomenological enquiry. In this way, the effect of fatigue could also be explored, a factor that seems to be overlooked in the literature concerned with the cognitive function of the cerebellum and the lived experience of cerebellar ataxia. The majority of participants in this study suffered with extreme fatigue that curtailed meaningful activity and full participation in their social world. The fatigue experienced by people living with ataxia in itself would benefit from further investigation along similar lines to that conducted into the experience of fatigue in multiple sclerosis (e.g. Hadjimichael et al. 2008 and Kos et al. 2008).

#### 6.6.4 The Emergence of Space in Ataxia

Ordinarily, to reiterate Merleau-Ponty's position (1945 [2002]), we have an immediate and concrete sense of ourselves and an intuitive sense of our personal space that is built up through established repertoires of behaviour. We may have a conscious appreciation of geometry, vectors and planes of movement but it is not this understanding of space that is used when we go about our everyday activities. For example, we perceive distances as reachable, within arms length, or walkable, we understand edges as corners to walk around, depth as kerbs and steps to be stepped down, and openings as affording passage. Rather than living in geometric space, our body, in Merleau-Ponty's words 'inhabits' (2002 [1945]:161) a practical or lived space i.e. our bearings are taken with reference to what it is we want to do, with reference to our motor intentionality (Morris, 2008a). In other words our usual orientation to space is pre-verbal and minimises cognitive effort. In illness and injury this understanding of the lived body and lived space is thought to breakdown as the capacity to integrate self and world becomes problematic (Merleau-Ponty, 2002 [1945]). This was particularly the case in the experiential narratives of participants in this study, highlighted with reference to Bill, Toby, Stella and Graham. Not only had their bodies become part of the content of their thoughts but also the immediate environment had emerged from relative anonymity to become something to contend with, to actively negotiate. This understanding of space and the immediate environment refers not only to locomotor space (for example Stella and the kerb, and Toby and the corridor) but also the immediate body-space negotiated by Bill, getting food onto the fork, coordinating the movement of his hand towards his mouth, timing this activity with his attempts at joining the conversation:

*'...the big frustration is not being able to eat and speak at the same time'*

It is not easy to reveal a person's relationship with space because it is concealed and subsumed in their everyday actions (Merleau-Ponty, 2002 [1945]:117). Movement is ordinarily orientated to body-centred co-ordinates and pragmatic spatial references that are outside conscious awareness (Gallagher, 2005). Under ordinary circumstances the body makes sense of stimulation and organises movement with reference to the body's practical intentions (Gallagher, 2005). This meeting and organising happens on the margins of consciousness. For example, it would be impossible to convey how people negotiate kerbs, avoid each other in a crowd, walk on uneven ground or as with Bill manage to chew, swallow and speak all at the same time.

Space therefore is not encountered passively nor, like movement, is it configured in the mind: 'movement is not thought about movement, bodily space is not space thought of or represented' (Merleau-Ponty, 2002 [1945]:159). This statement does not deny the existence of spatial or cognitive maps, rather it emphasises that in action such maps are not passive or simply theoretical representations of space. Merleau-Ponty seemed to anticipate an understanding of lived space consistent with the more contemporary ideas of embodied cognition (Wilson, 2002; Cowart, 2005). For Merleau-Ponty (2002 [1945]), we are not merely "in" space but we move through it. In order to negotiate space we construct a practical understanding of it using only features of the environment relevant to the task (Morris, 2008a). This means that the environment is represented, and understood in sensorimotor terms, as a kind of spatial-motor schema embedded in action, rather than in abstract or purely geometric terms (Cowart, 2005). The functional significance of the spatial-motor schema is that only the salient features of lived space are represented, permitting individuals to interpret their environment quickly without the need for time consuming processing of irrelevant information. Such "on-line" bodily intelligent action is particularly important in activities such as walking which require continuous updating in response to changes in environmental conditions, such as those that involve encounters with other people (Wilson, 2002). Not only does this save time but by using a sensorimotor representation of space rather than a representation that faithfully mirrors all the features of the environment, (the relevant as well as the irrelevant), the body is able to make sense of its environment through something it is already familiar with: itself and its interactions with the world (Cowart, 2005). Therefore, Cowart (2005) argues, if sensorimotor capacities determine how the world is experienced, impairment of these capacities (such as in ataxia) will fundamentally alter how an individual interacts with their world.

Returning to Stella, for example, rather than her body being the 'first co-ordinate' (Merleau-Ponty, 2002 [1945]:115) the anchor between her body and the situation of her body, her sense of "here" had to be cognitively reappraised as attention was directed towards the position of her body in relation to other positions and external co-ordinates ('*going through the door*' or '*going off the pavement*'). In this sense, as suggested by Toombs (1988) with reference to her own experience of MS, spatiality constricts to the immediate parameters of direct concern to the task being undertaken. At the same time, thinking about space slows Stella down, she has to go back for her body, ('*my limbs don't move fast enough for my head*'). For Toby, the corridors at work assault his progress as he is unable to call up or "meet" the particular body style invited by the spatial configuration of the corridor. Toby not only experiences his body as disrupted, he

also experiences a disruption of the easy communion with the environment that he would previously have taken for granted. Again, in this situation, as suggested by Toombs (1988) functional space takes on a problematic character.

This disruption of lived space is also seen in other conditions. For example in visuospatial agnosia the world is encountered in new and unfamiliar ways, it is perceived as an obstacle to one's intentions rather than as comprising tools and objects that facilitate functional activity (Lampinen and Tham, 2003). This experience differs from that described by the participants in this study in that people with visuospatial agnosia fail to recognise features of their home; objects in particular are no longer incorporated into ways of doing things, which makes people with this condition feel anxious and bewildered in everyday settings (Lampinen and Tham, 2003). People living with ataxia seem to have a similar sense of having difficulty in being able to cope with their surroundings, but this is more to do with the loss of skilful interaction not because they are unable to recognise objects and places for what they are.

The findings discussed here cautiously suggest, with reference to the particular experiences of the participants, that ataxia should be understood as more than a physical imposition. Living with ataxia disrupts the normally smooth way in which the body encounters the lived environment, and renders it problematic, hostile and therefore obstructive to participating in the world on one's own terms.

### **6.7 Conclusion: The Interaction of Body, Mind and Space in the Lived Experience of Cerebellar Ataxia**

What seems to be forthcoming from the detailed analysis presented here, is that in living with ataxia not only had the participants lost the sense of their bodies as anonymous and peripheral to consciousness, but they had also acquired a heightened awareness of cognitive processes and the fragile capacities of the mind, and in doing so had lost their unreflexive grip on the world. Participants recounted experiences in which formerly spontaneous, subconscious habits of the body were not easily, accurately or efficiently replicated via deliberate cognitive planning or indeed even readily constituted in thought. Their bodies no longer fully operated at a subconscious level and, however hard they tried it seemed that their conscious mind was unable to compensate for this loss of bodily intelligence. The physical environment emerged as something to contend with and thought-fully navigate in a way that contrasted with their previous experiences. Nonetheless, although their body and their way of being in the world was in many ways

very different from their previous way of life, the majority of participants did not reject their body or understand it as something alien to the self. This marks a significant new finding. The consequences of living with this particular ataxic embodiment were significant and debilitating. Participants talked about the effect of fatigue on their lives and the way in which this curtailed and circumscribed what they were able to plan for and achieve in their daily lives. This aspect of living with ataxia is under-explored in the literature and is worthy of further study.

This analysis focussed heavily on the embodied experience of ataxia which is an important and overlooked aspect of this condition. However, significant features of participants' lives have been intentionally set aside in the presentation and discussion of this theme, particularly those concerned with living with ataxia in public. The next chapter focuses on participants' accounts of their social world, and provides a detailed discussion of the social significance of living with disrupted embodiment.

## Chapter 7

### Super-ordinate Theme 2

#### *'I don't want to seem handicapped in any way' (Stella)*

**Description: Identity, stigma and disrupted embodiment in public spaces and places**

#### 7.1 Introduction

This chapter explores the participants' experiences of living with a problematic self in public. The analysis and discussion develop a contextualised, experiential understanding of the significance of this particular form of disrupted embodiment in public. Dividing these two themes into public and personal realms remains somewhat artificial but functions to present the data in a more coherent fashion than would otherwise be possible.

The understanding of public space used in this chapter takes its definition from Seamon (1980:161) as 'lived-space', the 'spaces, places and environments in which a person typically lives and dwells'. A local geographical world made up of, for instance; high streets, offices, supermarkets, cafés and the doctor's surgery. These are places of everyday life intimately connected with personal expression and impression management (Goffman, 1959). This chapter attempts to privilege and make sense of the participants' lived experience of stigma. It aims to convey what it is like to be in the complex situation of actively constructing a personal identity, whilst at the same being an unwilling focus of stigmatising forces that contribute to an individual's lived reality (Osyerman and Swim, 2001). Yang et al (2007:1530) characterised stigma as rooted in intersubjective space and as threatening the 'lived value' of what matters most in a person's local world. It is this view of stigma that best captures the stance taken with respect to understanding and analysing the stigma experiences of participants in this study.

The majority of participants (eight) spoke about the lived experience of ataxia in terms that suggested that it was a discreditable way of being in the world. The personal and social significance of disrupted embodiment unfolded in a number of different contexts. The quotations offered in Table 7.1 demonstrate the different ways in which participants talked about stigmatising experiences or concerns. Participants' accounts seemed to suggest that bodily disruption and incapacity invited critical scrutiny and disclosure of the self as socially improper and / or as harbouring a characteristic that was in some way

undesirable or diminishing. Participants differed in the ways in which they responded to stigmatising situations, therefore, where possible and in keeping with Smith's (2011a, b) arguments about quality in IPA, several examples from each participant have been included in Table 7.1 (pp. 145) to demonstrate this range and diversity.

This theme is constructed and presented using the accounts of five participants starting with Jim, and followed by Stella, Susan, Julia and Harry. Extracts from these participants were chosen because they were particularly powerful and most clearly conveyed what was shared as well as the individual diversity within this theme. Each account is presented in detail because participants offered a slightly different dimension of experience based on their individually situated perspectives. Looking carefully to differentiate the subtle variability across individual texts retains the idiographic commitment underlying the methodological focus of this study. The narratives do however share some common ground, and therefore similarities as well as differences have been considered and discussed. Extracts from the other participants have been used to indicate the extent to which experiences are shared across the corpus.

**Table 7.1 Ataxia as a Discreditable Way of Being in the World (n = 8)**

Participant	Extract	Page: line number
<b>An Unwilling Focus of Stigmatising Forces</b>		
Jim	<i>'You can realise very simply there are loads of pairs of eyes going chu-chu-chu – looking at you and thinking 'What's wrong with him?''</i>	14:31
Stella	<i>'If I think people are watching me I just freeze and my legs won't work'</i>	5:38
Stella	<i>'Well of course he was watching me and so were two other people so I couldn't walk very well.'</i>	6:18
Stella	<i>'You know I don't want to seem to be handicapped in anyway.'</i>	6:35
Stella	<i>'I don't flow as normal people do.'</i>	6:42
Susan	<i>'I don't like to go into the social situation where I feel I'm being judged.'</i>	7:25
Susan	<i>'I'm sure they look at me and think 'Well you've forgotten your stick and you're walking alright.' And I just don't want that sort of judgement. I find it easier not to socialise and I can manage without socialising really.'</i>	8:1
Julia	<i>'Because I don't want to seem odd in public it makes me very cautious.'</i>	7:28
Julia	<i>'I won't do things that might cause offence.'</i>	7:34
Julia	<i>'I have to make sure I don't have alcohol on my breath if people help me out because they'll assume.'</i>	10:11
Bill	<i>'You get used to being looked at, and you think well it would be nice to do things anonymously and not be the character in the wheelchair that everybody looks at.'</i>	5:3
Harry	<i>'As you go round the pool they all move around, opposite end. I don't know if they all think it's catching.'</i>	22:27
Toby	<i>'Particularly if people were behind me, walking behind me, because I'm aware that someone's behind me that tends to make me worse.'</i>	8:10
<b>Rejection of Stigma Symbols</b>		
Jim	<i>'Something so obvious as a walking stick, it's just a visible sign to everybody – yes I am definitely different.'</i>	14:48
Stella	<i>'I wouldn't go outside in the street with a stick.'</i>	6:30
Harry	<i>'You're equal to everybody else. When you're out there [participating in aeronautical sports] nobody can see the wheelchair.'</i>	5:20
Harry	<i>'I've always wanted to have a bike, fit in with the guys.'</i>	3:15
<b>The Discrediting World of Work</b>		
Jim	<i>'I went from feeling part of the [team, at work] to just ... well you're still part of the [team], but 'you're here because you're disabled, and we're going to keep an eye on you, wrap you in cotton wool.'</i>	5:6
Toby	<i>'And the managing director proceeded to say [...] 'we've decided you can no longer do your job' [...] And I said 'But why? I've given you no cause for concern.'</i>	4:1
Harry	<i>'And they didn't have a ramp into the new building. So for a year I was bumped up and down the stairs.'</i>	28:19
Hugh	<i>'I've got a computer [at work], that's a state, it's got a [really small screen], it's not very good, not big enough, I've asked for a bigger screen but I haven't got that [...] basically I'm being put to one side really, [...] they seem to be making it harder for me.'</i>	17:36
<b>It's not only Strangers who Stereotype or Judge</b>		
Susan	<i>'My daughter doesn't leave them [the grandchildren] with me very often. And I wonder if she thinks I can cope.'</i>	8:23
Julia	<i>'Whenever we cross the road he [Julia's son] always holds me by the scruff of the collar. I say to him 'Have you any idea how that makes me feel?''</i>	11:20

## 7.2 Jim

The following offers a detailed examination of Jim's account. Jim had lived with cerebellar ataxia for over twenty years. He spoke at length about his experiences and the complex ways in which he chose to confront, as well as come to terms with, what

might be understood as a discreditable condition. At the time of the interview he was in his late forties, working full time and living with his wife and two teenage children. He was able to walk independently indoors and outside although outdoor mobility was becoming problematic. In this first extract Jim was asked to talk about how ataxia affected him physically:

*'I'm aware that my general gait when I'm walking makes you look like you're drunk [...] which causes problems, just generally when you're out, when you're out shopping or you're just out walking. And yeah, sometimes you do stumble and fall down. It isn't a problem for me, but I'm aware that other people because of their preconceived ideas about it probably think 'Christ, he's had too much to drink' or 'What is he doing?' Which again I try to look on the positive side, what people think doesn't affect me. But it does make me very upset and slightly angry when you're with your family, because people do make hurtful comments. You can see people's eyes just burning holes through your back. But again I've learnt to deal with it and you become hard skinned and hard nosed ... but for my wife and kids, it's sometimes difficult to accept. [...] So me at work um ... part of my job involves working in big offices [...] and when you walk about there or when you're talking to somebody you can realise very simply there are loads of pairs of eyes going chu-chu-chu – looking at you and thinking 'What's wrong with him?' I think that is probably the biggest problem that anybody with I suppose any disability has coming to terms with it, accepting that you are different.'*

A phenomenological reading of this passage might suggest that it is Jim's emotional experience and not his physical experience that is foregrounded. The visibility of the symptoms of ataxia in the public domain and the connotations of drunkenness draw unwanted attention in the form of the "stare" which is a continual reminder of difference. The stare is powerful; it burns holes in his back and penetrates him - 'chu-chu-chu', (this sound effect was accompanied by a stabbing gesture). He describes feeling angry, upset and hurt by what he perceives as a public judgement of him as 'wrong' and 'different'. So, although physically the ataxia unbalances him and causes him to fall, what concerns him most are his assumptions about other people's responses and beliefs about what this disordered walking signifies about him. In this sense ataxia could be understood as a stigmatising condition: disordered walking as a visible and undesirable characteristic of ataxia draws unwanted attention. This in turn provokes feelings of distress or shame arising from the consciousness of something in one's own behaviour that is in some way discreditable or offensive to others.

Jim's interpretation of his status as *'different'* resonates with the experiences of people living with other movement disorders, such as Tourette Syndrome (Davis et al.2004), Parkinson's disease (Bramley and Eatough, 2005) and multiple sclerosis (Grytten and Måseide, 2006). These findings correspond with Goffman's (1963) original formulation of stigma which referred to an 'undesired differentness' (p15), 'an attribute that is deeply discrediting' (p13) which works to reduce an individual 'from a whole and usual person to a tainted, discounted one' (p12). In this model, the stigma is located *within* an individual, it is a difference, a 'mark or sign' that signifies the bearer as deviant or flawed (Jones et al.1984:5) or devalued (Crocker et al.1998), but the stigmatized social identity only comes into being in local social contexts. For Goffman (1963:12) stigma therefore creates a discrepancy between a 'virtual social identity' that is inherently spoiled (how the person is understood by society; an identity ascribed by others) and an 'actual social identity' (who the person really is).

Jim seems to assume that his virtual social identity is marked by two diminishing labels, possible intoxication (*'Christ, he's had too much to drink'*) and inappropriate bodily formulations and actions at work (*'What's wrong with him?'*). Alcoholism, the associated dependency and particularly the blameworthiness linked to what might be understood as an irrational behaviour, ranks close to the bottom of acceptance hierarchies of different illnesses and disabilities (Dear et al.1997). A person who appears visibly drunk is also likely to suffer social exclusion because other people (especially work colleagues) would consider it "wrong" to appear in public in this condition (Room, 2005:148). Bodily disorder in itself is also thought to signify a lack of control or untidiness that is not well tolerated in Western society (Yardley, 1997). Davis et al (2004:105) suggested that people with salient physical differences, like Jim, are commonly labelled and understood by others as being 'irrational and disordered users of public space'. This socially constructed conception of what sort of behaviour is accepted in shared environments may have particular relevance for Jim, and others living with ataxia. It may represent a stereotype threat, the fear that as "members" of a particular group (e.g. alcoholic, physically impaired) their actions may in some way confirm the stereotype associated with the group (Steele and Aronson, 1995).

Physical incompetence, unpredictability, and possible intoxication breaches widely held beliefs about what is acceptable in public environments. Understanding himself as different and stereotyped in this way might suggest that Jim not only accepts this frame of reference but he may also believe it is part of his actual identity. Internalising the beliefs associated with a particular stigma draws on 'self-schema' theory whereby

individuals build an understanding of the self that is based on stigma which then assumes a position of importance within the self-concept (Jones et al.1984:115). From a social model of disability perspective this devalued sense of self could be understood as a form of internalized oppression (Thomas, 2007; Swain and French, 2008; Oliver, 2009). Jim might also have a high 'stigma consciousness' (Pinel, 1999:115). He seems to expect to be judged on the basis of his membership of a devalued group and appears to be on high alert for signs that he is being appraised in a negative way instead of being judged on personal merit. This in turn may limit the ways in which he is able to overcome his assumed status. However, this analysis is just the first step in trying to understand how Jim makes sense of and responds to significant events that take place in public space and, as discussed below, it only represents one dimension of what appears to be important and interacting elements of Jim's lifeworld.

At a more hermeneutic level the above extract might suggest that Jim is engaged in an existential struggle to determine what meanings he foregrounds. On the one hand, he tries to minimise the stigmatising consequences of living with ataxia (*'It isn't a problem for me', 'what people think doesn't affect me', 'you become hard skinned and hard-nosed'*), yet on the other hand, in public, he seems to be confronted with experiences that challenge this perspective and he describes strong emotional responses even whilst claiming indifference. One reading of this interpretation might suggest that Jim is engaged in cognitive work in an attempt to contain what is in fact uncontainable and at large. However, it seems that what is constructed through this self-talk is fragile; although Jim tells himself that the ataxia is no big deal and not his problem, what is revealed in his experience in the world – his practical engagement in the world – is the opposite. It is, he believes, a big deal to others; people attend to it and judge him by it.

Jim's account suggests that coping with stigma is never a "done deal". Managing stigma experiences seems to be a dynamic and on-going process intertwined with coping with other aspects of living with ataxia in his personal and social world. Sociological approaches to stigma understand difference as a socially created phenomenon, the product of a particular social situation, determined by a variety of factors that are not within the power of one person to constrain (Dear et al.1997; Major and O'Brien, 2005). In one sense, Jim seems to have understood this broader conceptualisation. Through serendipitous means, Jim engaged with disability rights advocates. He supported others living with ataxia and informed the public in general about disability issues. Jim had also met and become friends with a work colleague who was also trying to make sense of her own discriminated status. Gaining an understanding of disability rights appears to

help some individuals to cope with stigma (Ablon, 2002) and these experiences seemed to provide Jim with a clear philosophy and an affirming rhetoric which he might use to reframe his sense of self;

*'I think 'Well it isn't my problem, it's your problem.' And if my speech or balance or anything else causes any inconvenience, if I fall down, well I'm used to it, it's not a problem to me. If it offends anyone else, if it troubles them – that's their problem.'*

Jim seems to be engaged in 'cognitive restructuring', a voluntary coping process described by Miller and Kaiser (2001:81) as a response to stigma-related stress that involves changing the meaning of a particular situation or experience by devaluing the emphasis others put on a specific attribute or behaviour. Jim spoke of making a 'conscious decision' to adopt 'a whole different philosophy' and now considers himself a 'bit of an ataxia zealot'. His enthusiasm here has an almost religious quality (or at least that is the metaphor he is using) which perhaps reflects Jim's firmly held beliefs about the importance of what he is doing. It may also be a sign of his need to protect or rescue others from the protracted and difficult experiences that he went through and, it seems, is still living through. Making a strategic decision to take a stand and to talk about personal experiences in public settings, so called "broadcasting", is thought to be self-affirming because it cultivates a sense of power over the condition and the stigma itself (Corrigan et al.2009). Jim therefore seems to be engaged in actively constructing a more positive and valued identity than the virtual identity shaped by his stigma experiences. However, as noted above, this is an uncertain enterprise. In this next extract Jim described how he feels about using a walking stick:

*'I should use a walking stick, I've got one in my bag, but I'm still coming to terms myself with the fact that I need to use it, being seen to be using it ... which is more about my own preconceptions and image I suppose. And I'm aware, I guess, longer term ... if it does get worse you could end up in a wheelchair but it's just something personally I find it very difficult to consider [...] You're self conscious anyway, which can create its own problems but having something so obvious as a walking stick, it's just a visible sign to everybody – yes I am definitely different. [...] because rather than use a walking stick I'd just hold onto [my wife's] hand or use [my children] as a walking stick.'*

Here Jim refers to the visibility of a stick; 'being seen to be using it', 'having something so obvious as a walking stick', 'it's just a visible sign to everyone'; he seems to see himself through other people's eyes and through them he formulates walking with a stick in negative terms; being 'different'. But perhaps at a deeper level this passage touches

on Goffman's (1963) ideas about containment and concealment of stigmatised identities. Jim acknowledges that he needs a stick but has not come to terms with this yet. Although he carries a stick in his bag, it appears that using it would also perhaps be an admission of something that he is not ready to accept; a visible sign that the ataxia is looming large and cannot be kept in check in the public domain. It might be important to recognise that Jim seems to be in a period of transition; moving from independent walking to walking with a stick. Jim seems to be in flux, not only physically but also in the sense of understanding what this change in physical capability might mean. He is not reconciled with what he understands through his own experience (*'still coming to terms with the fact'*) and this creates what could be understood as a cognitive dissonance (Festinger, 1957). Walking with a stick provides further confirmation that ataxia is now a problem for Jim and therefore serves to deconstruct his attempts to play down its significance. He engages in normalising behaviours, using his family as proxy-sticks to help him walk rather than using the stick itself. These behaviours may help sustain a sense of self that is "normal", he is "normal enough" to be in a relationship and may also fulfil a need to present a "normal" self to others (Radley, 1993). The walking stick might also be considered a stigma symbol; it serves as a signal of difference to others. The stick may be regarded as an artefact that symbolises a group identity that sits uncomfortably with Jim. However, more importantly, the walking stick and the almost unbearable thought of becoming a wheelchair user (he switched from 'I' to 'you' at this point in the narrative, a sign perhaps that he is not ready to accept this prospect) cast a shadow over the present, projecting Jim into a possible future that he is not yet ready to face.

In this sense Jim seems to be coping with multiple identity threats, not simply a virtual identity constructed through stigmatising experiences but also threats to his identity based on assumptions and fears about his future self. Markus and Nurius (1986) introduced the concept of possible selves as formulations of a particular self-image constructed from individually relevant sociocultural and historical contexts and immediate social experiences. Possible selves can be hoped for or feared. Dominance of one possible self-concept over another (the 'working self-concept') is determined by an individual's response to an event or situation; if these experiences are negative, the working self-concept will be oriented towards negative (or feared) possible selves. If these conceptions are particularly powerful, in terms of their ability to define the self, then they can become 'chronically accessible' as the default view that a person has of himself or herself (Markus and Nurius, 1986:957). Jim sometimes seems to have the energy and resources to confront some of these threats to his self-image, for example

by holding onto and forging a preferred identity, an independent and competent self who also has much to offer others who face similar difficulties. However, it seems that what he fears most, his possible future self, is chronically accessible and creeps into his lived world even though he tries to block it out. For Jim, even though he describes himself as an *'ataxia zealot'* and he seems to know about the social model of disability, these are salient fears. These examples provided further insights about the kinds of issues Jim was grappling with and his possible difficulties with cognitive dissonance. Major and O'Brien (2005) posit that identity threat occurs when an individual appraises stigma-relevant stressors as potentially harmful to their social identity and as surpassing available coping resources. Jim's experience suggests that identity threat is a dynamic and unfolding concept that occurs in conjunction with other threats to psychological and emotional well-being.

Interpretative work therefore cautiously suggests that stigma could be identified as a concern within Jim's account. Perceiving himself as separate and different could be understood as reflecting a negative socially constructed view of physical impairment. These perceptions may reflect Scambler's (1998:1054) ideas about 'felt' stigma, or fear of discrimination, but also 'enacted' stigma or actual discrimination (*'because people do make hurtful comments'*). It seems that Jim has internalised a view that frames disordered walking as undesirable and possibly shameful and this is inferred through his encounters with others. In order for the internalisation to work there must be at least some agreement between the self and others that the difference is inherently undesirable (Coleman, 1986). Jim's on-going efforts to keep the ataxia from looming large could be understood as a means of resisting the perceived stigma associated with disordered walking but also, in a more existential sense, as a means of keeping the ataxia and its longer term implications at bay. For Jim, *'Accepting that you are different'*, is an undertaking that is closely woven into other aspects of living with a long term progressive condition. The stigma associated with disordered walking cannot be disconnected from or dealt with separately from his other existential concerns (such as the looming wheelchair). It is another phenomenon that threatens the things he values most and therefore, as suggested by Yang et al (2007:1528), the stigma serves to 'intensify the sense that life is uncertain, dangerous and hazardous.' This might explain why Jim may find it difficult to consistently resist the damaging effects of what he perceives as stigma related events. Furthermore, Jim's account has revealed that in spite of having what appears to be an intellectual understanding of the social model of disability, this sort of cognitive knowing has not relieved him of his emotional wrestle with feelings of difference and discreditation. Grappling with the inconsistency between

what he “knows” and what he understands from his own experience, seems to support the interpretation that Jim lives with an enduring sense of cognitive dissonance and unrelieved psychological discomfort.

### 7.3. Stella

The following extract is taken from Stella’s account, and is used to demonstrate the extent of the shared theme but also the subtle differences involved in her interpretations of her experiences. Stella was in later mid-life; she was retired and lived alone. Stella had lived with ataxia for over ten years.

Stella: *‘I have this nervous thing as well, this is another phobia. If I think people are watching me I just freeze and my legs won’t work.’*

Interviewer: *‘Okay’*

Stella: *‘And for a moment I can’t move my legs. And then I gradually sort of stumble about and then once I’m over that initial nervousness ... so the head is very ... the brain comes into this a lot really.’*

Stella seemed to share similar concerns with Jim and may have had a similarly high ‘stigma consciousness’ (Pinel, 1999:115). However, Stella’s responses were uniquely situated in that public scrutiny, *‘If I think people are watching me’*, effectively paralysed her, *‘I just freeze and my legs won’t work’*. From a phenomenological perspective, it seemed that Stella had also come to understand that walking disclosed something about her that others considered discreditable, i.e. that she was in some way personally responsible for her stigmatised status, a form of internalised oppression. People may not actually stand in judgement of her and she may only *‘think’* that she is being watched, but for Stella even just the thought of being watched had a profound effect. This is not uncommon. Knowledge about widely recognised stereotypes and their possible relevance to an individual can change behaviour even in the absence of potential stigmatisers (Major and O’Brien, 2005).

Momentary “freezing” could also be understood as a means of temporarily resisting what Stella anticipates as a harsh and potentially overwhelming public appraisal. Yang et al (2007:1531) suggested that stigma may have ‘psychobiological manifestations’, in the sense that what Stella described is not simply a socially constructed phenomenon but is the actual ‘embodiment of a sociosomatic process’. “Freezing” in this sense could be understood as the bodily manifestation of an involuntary stigma coping strategy (Miller and Kaiser, 2001). A brief paralysis, or disengagement from the situation, might give

Stella pause, a short-lived hiatus where she can shore up her resources, bolstering herself to withstand and manage her disrupted embodiment.

Stella may “freeze” because she is also concerned about and possibly fears confirming her stigmatised status. Stigmatised people who are unable to regulate intrusive thoughts about manifesting stereotyped behaviours may be less able to resist their deleterious effects (Miller and Kaiser, 2001). Schmader et al.(2008) suggested that people who demonstrate hyper-vigilant responses to stereotype threat seem to have difficulty resolving competing cognitions based on trying to forge a positive link between self and place whilst at the same time resisting negative links. This contest may overly burden executive function, even for tasks such as walking that are usually managed automatically. In this sense Stella may “freeze” simply because processing the sort of threat posed by the stigma depletes cognitive resources (Klein and Boals, 2001) and these resources may already be diminished by the cognitive effort involved in walking (as discussed in the previous chapter). Therefore it seems that both the disordered walking and “freezing” are problematical for Stella.

At a more hermeneutic level, the pauses in the above extract seem to signify that Stella found it difficult to account for “freezing”. Trying to make sense of it, she gives it a name; *‘nervous thing’*, *‘phobia’*, *‘nervousness’*, but this does not seem to capture what it is she experiences. She continues to search for a better explanation; *‘head’*, *‘brain’*, but direct access to the meaning of this experience seems to be just beyond words. Later in her account it emerged that Stella had described this problem to her consultant who gave it a diagnosis: *‘phobia’*. Stella seems to struggle with phobia as a valid interpretation of her experiences, perhaps because of the implication that it is in some way irrational. Such labelling might suggest to Stella that she should be able to resist and ultimately overcome this particular problem. Returning to Goffman’s (1963) terms, Stella may therefore have a problematic virtual social identity: a stigmatised identity and a medically constructed phobic identity.

So Stella, like Jim, has difficulty walking and she also has difficulties with self-consciousness in public. It seems that Stella assumes that she bears a stigma, and as with Jim, Stella infers that her disordered walking will draw critical appraisal. “Freezing” further complicates this picture; it carries a diagnosis which in itself is pejorative. Stella may also feel responsible for this behaviour, as if the *‘phobia’* is her fault. Unlike Jim, Stella did not talk about disability rights and there was no evidence in Stella’s account of the sort of cognitive re-structuring evident in Jim’s narrative. This may have adverse consequences for Stella because this type of voluntary coping mechanism is thought to

have protective effects through promoting psychological adaptation (Miller and Kaiser, 2001). One further extract from Stella's account adds another layer to this analysis:

*'I wouldn't go outside in the street with a stick. I make myself [walk without the stick] ... because I want to be able to be free as long as I can. Now whether that's the right attitude I don't know. But I suppose it's pride in a way isn't it? [...] You know I don't want to seem to be handicapped in anyway.'*

As with Jim, the walking stick is an additional signal of difference that is assumed to attract unwanted attention and critical appraisal from others. Stella does not want to be seen using a walking stick for fear of being judged as *'handicapped'*. Being seen in this way is diminishing for Stella. She explains this in terms of *'pride'*. It seems that Stella walks without a stick in a deliberate attempt to maintain her personal dignity, her sense of self. Drawing on Yang et al (2007), what seems most at stake here is Stella's positive sense of self; the idea of being *'handicapped'* subverts this preferred identity. Stella also frames the walking stick itself as dis-abling; it is almost as if the stick in some way tethers her, limiting her freedom and independence. There is also a temporal quality to this passage; *'I want to be free as long as I can'*, the walking stick seems to prompt Stella to anticipate the time when she will no longer have the freedom to choose whether to use it or not. Again, possibly at a period of transition, the landscape of Stella's being-in-the-world seems to shift as a seemingly inevitable but unpredictable decline is foregrounded.

In both these extracts Stella seems to anticipate the scrutiny of others as shameful and demeaning. Stella's episodes of paralysis and her rejection of the walking stick could be understood as a way of resisting disclosure of what she assumes or fears is an imperfect self. Refusing to use a walking stick may also fulfil an important need to retain an existential sense of personal freedom and control in the face of potentially inescapable and progressive disability. There are similarities with Jim's account, particularly with reference to inferred stigma brought upon by disordered walking which is further complicated by the introduction of a walking stick. Both accounts also reveal a temporal orientation to do with keeping a possible future self, one who is both more impaired and dependent, in the "not yet" rather than the "already" realm of personal experience.

People, like Stella, who are unable to tune out every day stresses that arise from assumed prejudice, may find it difficult to overcome this sort of chronic strain if their coping mechanisms are unsuccessful (Miller and Kaiser, 2001). The sort of coping

mechanism Stella described, whether voluntary or involuntary, seemed to focus on avoiding negative consequences rather than promoting more optimistic outcomes. Over time these sorts of strategies are thought to be psychologically depleting (Shih, 2004). Jim, by comparison, seemed to have a strong sense of injustice and adopted an active, more empowered response to stigma, at least on a cognitive or explicit level. This approach perhaps helped to deconstruct his virtual identity and, although by no means straightforward, could act to replenish his sense of self, especially over the longer term (Shih, 2004). Jim's more confrontational stance, his sense of righteous anger, as well as his advocacy role and group identity seems to fit with a model of stress response that is more likely to develop resilience (Shih, 2004) and personal empowerment (Corrigan et al. 2009), and may also work by externalising through attributing blame to others instead of himself (Major and O'Brien, 2005). Stella, on the other hand, seems to have more difficulty, at least in the short term, in actively resisting her stigmatised status. She is a member of a support group but finds it difficult to get to meetings, and possibly lacks the supportive networks that are thought to be important in sustaining or helping to reconstruct a valued sense of self.

#### **7.4. Susan**

Here, an extract from Susan's account is introduced which has a slightly different quality from the accounts considered so far. Susan was in later mid-life, retired and lived with her husband. She had lived with ataxia for many years but was not certain about the date of onset or diagnosis. Like Stella and Jim, Susan talked about a social situation where she anticipated unfavourable scrutiny and disapproval not because her disordered gait as such drew attention, but because it was inconsistent and perhaps not "bad enough" to be accepted by others;

*'My social life now tends to be on the computer – e-mails to people with ataxia. I don't like to go into the social situation where I feel I'm being judged. So I've got a bit of an inferiority complex really so I don't like to go out. I don't like to be in family gatherings cos I feel so unsure of myself. [...] I just feel that people are judging me. You know if I want to get up and go to the Ladies I think people are going to watch me. Because they've heard that I've got ataxia and they think 'Why does she need a stick?' or you know ... 'She doesn't seem that bad'. Just I don't want to be judged. Cos sometimes I forget it and I'm sure they look at me and think 'well you've forgotten your stick and you're walking all right'. And I just don't want that sort of judgement. I find it easier not to socialise and I can manage without socialising really.'*

Here, as with Jim and Stella, there is a concern about being watched, *'I think people are going to watch me'*, and about critical appraisal, *'being judged'*. For Susan, it seems she assumed that people, particularly extended family, pass judgement not necessarily about her disordered walking but about the legitimacy of her condition. She inferred that fluctuating disability perhaps lacked credibility. Susan did not always need a walking stick; she could manage if she was not too tired or if she could reach for furniture for support. Susan seemed to assume that this inconsistency was misunderstood by people who knew about the ataxia, *'She doesn't seem that bad'* and like Jim, she ascribed behaviours (e.g. hostile stares) and expressions (critical voices) to these "others" who she believed stood in judgement of her. In this sense Susan, like Jim and Stella, might have a high stigma consciousness. Rather than face delegitimation, Susan has taken what seems to be the rather drastic step of withdrawing from most face to face encounters with others. Similar to Jim, Susan engages in self-talk; *'I find it easier not to socialise and I can manage without socialising really'*, possibly as a means of justifying or minimising the possible negative consequences associated with retreating from social interactions.

Escaping to a private world where "rule breaking" is more readily tolerated has also been recognised as a stigma avoidance strategy used by people living with Parkinson's disease (Nijhof, 1995). Disengagement from physical and social domains in which one's self-esteem is threatened is a recognised voluntary coping mechanism (Miller and Kaiser, 2001; Major and O'Brien, 2005). Physical withdrawal or avoidance often coincides with membership of self-help groups that are unlikely to reinforce a devalued status (Pinel, 1999). Susan does have a social life but it is confined to her closest relationships and other people with ataxia via the internet or support groups. Susan may feel safe in these environments and free from people who, she feels, would ordinarily disapprove of or censure her (*'everybody there's not going to judge me'*). Furthermore, as Susan is an active member of this group, she believes other members are *'grateful'* for the work she does on its behalf. This positive feedback, the sense that she is making a valued contribution, may in turn give Susan a stronger sense of self-worth. Susan therefore differs from Jim and Stella because she has opted to limit her social interactions to her closest family and other people who live with the same condition. Goffman (1963:31) refers to these as 'sympathetic others' or the 'wise', people who reinforce acceptance and put others at their ease.

On first reading, Susan's strategy of disengagement through avoidance might be considered as a passive and unhelpful means of reducing personally diminishing

experiences. Looking closely at the words Susan uses in the earlier extract (*'I find it easier not to socialise and I can manage without socialising really'*) suggests that she has perhaps settled for making do, rather than actually making a positive and concrete decision about withdrawing from most aspects of public life. However, by simply focussing on what she considers most important, her 'core lived values' (Yang et al.2007:1530), Susan may in fact be enacting Croker and Major's (1989:616) concept of enhancing self-esteem by 'selectively devaluing' dimensions of her experience in which she feels poorly judged, and focussing on what matters most (her family and helping others in similar circumstances). Miller and Kaiser (2001) suggested that although disengagement coping strategies may result in quite negative outcomes for some (e.g. failure to achieve goals in other valued settings), it might be inappropriate to stop people from using this type of stigma management strategy. For Susan, avoiding people who make her feel inferior, and seeking out those who enhance her self-esteem may be a personally suitable strategy, especially if she is unlikely to gain anything positive from these other encounters.

Unfortunately, this is not a stable or uncomplicated position; it does not seem to confer immunity from stigma in perpetuity, nor does it completely protect Susan from the harmful feelings associated with living with what she assumes is a stigmatised status. For example, Susan says that she has *'got a bit of an inferiority complex'*, which perhaps points towards feelings of personal inadequacy and self-doubt in the present that seem to stem from interactions with others in the past. These feelings may be strongly reinforced if her sense of self is threatened in places where she thinks she should feel most protected, for example at home. The following extract suggests perhaps that this is the case: *'My daughter doesn't leave them [the grandchildren] with me very often. And I wonder if she thinks I can cope.'* A theme of distrust from close others continues with this example. For Susan, it seems that her body cannot be trusted to be consistently impaired or unimpaired, and Susan cannot be trusted to look after the grandchildren. Such beliefs could be particularly devastating or pernicious especially because family members maybe the most frequently encountered, strongly connected and valued "others" for people living with discreditable conditions (Ablon et al.2002; Lee et al.2005).

Susan also differs in comparison to Stella and Jim because she did not perceive the walking stick as a stigma symbol. Susan claimed: *'the stick has really been my greatest benefit'*, without the stick Susan feels that she is *'toddling, walking a silly walk'* but if she uses the stick or simply takes her time and thinks about moving then she can *'usually carry on the same as anybody else'* or *'like there was nothing wrong with me at all'*. In

this sense the walking stick could be understood as enabling, or as allowing her to 'pass' (Goffman, 1963:95) so that her disordered walking does not draw unwanted attention. Social comparison, measuring herself against others, suggests to Susan that her walking is discreditable, 'silly', possibly childish, in other words that she is not a competent adult. The walking stick corrects this difference and offers a means of fitting in. "Passing" in this sense, actively constructs a virtual identity which is more in keeping with Susan's actual and preferred identity. The situation is complicated however, because in less challenging environments, Susan can cope without the stick. Inconsistent use of a walking aid, she believes, breaks the rules governing social behaviour and it is on this rule breaking rather than on her disordered walking or use of a walking stick where she feels she is judged.

For Jim and Stella, interaction in public spaces and places provoked critical self-appraisal, turning the same standards against themselves that others have used (or are assumed to have used) to judge them. Susan also infers harsh judgement for having a disability that (she assumes) lacks credibility. In this next example, Julia also seems to carry an assumption that her social behaviour is in some way unacceptable.

## **7.5. Julia**

Julia was in later midlife, retired and lived alone. Julia had lived with ataxia for over twenty years. The following quotation from Julia's account connects with the previous examples but extends the experiential understanding of what it might be like to live with disordered movement in a public space by drawing on a slightly different dimension of experience;

*'... because I don't want to seem odd in public it makes me very cautious, very slow in what I'm doing. When biscuits are passed round I don't take them because of crumbs, and I drink water when I'm anywhere else, because I don't want to spill things on other people's floors. Perhaps as I grew up you considered other people, but you were still independent. I'm much less ... I won't do things that might cause offence ...'*

The above quotation has some resonance with Stella's and Susan's accounts and seems to share the same concerns about infringing commonly accepted rules of behaviour in public that have been identified as salient for people living with Parkinson's disease (Nijhof, 1995). Julia differed from Stella and Susan though because she seemed to hold a belief that she had a moral responsibility not to offend other people. This strong sense of propriety was instilled in childhood ('as I grew up you considered

*other people*’) and possibly constitutes a deeply ingrained way of understanding the world. Julia’s disordered movement and its potential consequences might no longer meet her own high standards of socially acceptable behaviour. Rather than claiming indifference like Jim, Julia seemed to find “motor impropriety” personally unacceptable or even disrespectful if left unchecked, and she seemed to assume that others would too. Julia therefore used self-censoring strategies to reduce the risk of transgressing her own and, she assumed, others’ codes of behaviour, and to perhaps help preserve a more morally acceptable sense of self. As suggested by Goffman (1963:125) Julia’s strategy could be understood as a way of ‘covering’. Julia adopts a presentation of herself that is congruent with social norms and expectations. Covering behaviour is thought to reduce tension in a social situation where the stigma is already apparent, to make it easier to overlook the stigma and to sustain natural or spontaneous involvement with the stigmatised (Goffman, 1963). The same strategy is seen in the following quotation, the circumstances of which perhaps reinforce Julia’s view that her behaviour in social situations matters:

*‘I have to make sure I don’t have alcohol on my breath if people help me out because they’ll assume [...] Well, often people say you should take more water with it, but only joking. It’s not meant offensively. And I guess in shops, sometimes some people get anxious. They’re anxious when you’re not clear because they don’t know why.’*

These encounters and everyday discourses reinforce Julia’s beliefs about the validity of socially constructed rules of behaviour. Not all rules count but, as discussed previously with reference to Jim’s account, breaking specific rules about alcohol consumption in the wrong place, and at the wrong time, does seem to matter. According to Miller and Myers (1998) people like Julia could be understood as using compensation strategies to overcome the mismatch between available skills and social demands. As long as the level of prejudice is not too high (where it is assumed that prejudice would occur regardless of compensatory skill and effort) and the compensation has a reasonable chance of being effective, then potentially difficult social contexts can be safely negotiated and negative outcomes (*‘I don’t want to seem odd in public’*) avoided. In this sense, Julia’s strategies could be understood to work against the stigma by meeting her perceived obligations to safeguard the ‘moral order’ (Keusch et al.2006:526) and, in a similar way to Stella, by resisting disclosure of an imperfect self.

Taking the analysis one step further, it is possible to suggest that applying and maintaining the sort of self-surveillance Julia describes could be quite wearing and potentially quite restricting in terms of accepting invitations or participating in activities

outside her home. These sorts of behaviours, conforming to and adapting to the assumed expectations of non-disabled people, are also considered a form of social oppression (Reeve, 2002). By engaging in behaviours that control the presentation of the self in public, Julia is also demonstrating a coping strategy that is well recognised in the literature; primary-control coping. Although this type of compensatory behaviour may be effective in helping people achieve meaningful goals, it seems that it is not without cost (Miller and Kaiser, 2001). As her ataxia progresses, this strict application of rules that are assumed to govern social acceptability could place limits on the range and extent to which Julia is able to meaningfully participate in collective activities, and the degree to which she can derive a sense of satisfaction from these encounters. Furthermore, these self-monitoring strategies would seem to involve the same sort of conscious attention that Julia (and others) recounted with reference to the exhausting effects of managing disordered movement, as discussed in the previous chapter. DeJordy (2008) argued that impression management (such as that described by Julia) demands constant vigilance and is consequently cognitively taxing. Stigma management might therefore be understood as an additional contributing factor to the overwhelming fatigue described by the majority of participants in this study. This is because presentation of a publically acceptable self seems to entail on-going effortful self-monitoring and / or long-term emotional investment.

Consonant with Susan's experiences, close family members also seemed to sabotage Julia's efforts to reduce the salience of her perceived stigma. Julia's son for example seemed to reinforce feelings of inadequacy or incompetence:

*'Whenever we cross the road he always holds me by the scruff of the collar. I say to him 'Have you any idea how that makes me feel?'*

What Julia describes here seems particularly demeaning as she is commandeered and propelled across the road against her will. According to Watermeyer and Swartz (2008:604) Julia's son's actions might suggest an anxiety borne from a sense of needing to do something to help or rescue when faced with a another person's impairments which is then managed through an unsolicited 'doing response'. Although Julia almost laughs off this incident and possibly does not fully communicate the hurt involved, she could also in this instance be acting to shield her son from the potentially harsh judgement of the researcher. Julia's son's actions however, may represent an incursion into Julia's bodily and psychological boundaries that are strongly indicative of the oppression inherent in the social relations of people living with disability (Watermeyer

and Swartz, 2008). Such behaviour, particularly from a family member may be particularly wounding (Ablon et al.2002; Lee et al.2005).

### **7.6 Harry: Discrediting Experiences at Work**

Places of work are constituted by embodied action with others and are contingent upon interpersonal relations in local social and cultural worlds. Four of the five participants who worked, recounted discrediting experiences that would suggest that their employers treated them differently (and unfavourably) because of ataxia (Table 7.1, p145). Jim for example talked about being singled out as different because of an assigned special status (*'wrap you in cotton wool'*), a status that Jim actively resisted. Hugh felt marginalised (*'I'm being put to one side really'*) and pressurised at work (*'they try their best to snow me under so that I'd leave'*). However, it was Harry's account that perhaps most clearly communicated the complex undercurrents at play in the work setting.

Harry was in his early thirties, he had worked full time for the same company for just over ten years and was a full-time wheelchair user. When asked how important work was in the context of the rest of his life, Harry responded:

*'Basically, I work ... I work a hell of a lot. I don't take a lunch break, you know. I take pride in my work. I just do it to death really. And every time I go on holiday it [work] just tends to fall apart. It's quite enjoyable to watch, you know. Oh I am needed! (laughs) But they won't say that. [...] I'm always there if they need somebody to help [...] Yeah, so because ... it's really weird, because these people need help [...] because they need help you feel in a different position. They're actually asking a disabled person for help. So through that, people at work don't see me as disabled. Which ... that's what I want to be seen as, you know, normal bloke in a wheelchair.'*

Harry seems to perceive work as a place where he can be counted alongside everyone else, where his physical impairments are irrelevant and where, in his eyes, he has achieved a position of respect. Work in this sense validates his preferred identity *'normal bloke in a wheelchair'*, and subverts any sense that he is a victim in need of special treatment or help. Working long hours and always being available might be understood as contributing to identity management, weakening a disabled identity whilst projecting a more acceptable identity as perhaps a workaholic (*'I just do it to death really'*) or dependable employee (*'I'm always there'*). However, Harry's account also revealed a more complex picture:

Harry: *'it's funny cos they've always treated me the same as all the others, and now because I've started having to have different things ... well run out of steam [...] And they don't accept change very well. Flexible working. My big boss said 'I'm not condoning flexible working, I'm not having people taking time off', stuff like this. 'But we'll make an exception for you.'*

Interviewer: *'How did you feel about that?'*

Harry: *'I basically had to ... well I took it and just went with it. [...] They're fantastic people, don't get me wrong, but ... they get confused sometimes. It's like they don't have much money and we had to work somewhere else for a year until a new place was found and built. So for a year I was bumped up and down the stairs. But ... yeah. I tackled the big boss about it, and he said 'Oh yeah, we're saving money for the new building.'* And they put in a lift for me in the new building, so fair enough. So I could get everywhere in the new building which ... he thought made it ok for this portakabin, yeah. And it's difficult isn't it? You don't want to like say, you know. For 100 quid or whatever we could have quite a nice ... [ramp].'

Harry's account of his experiences at work seems to suggest quite a conflicted position: *'They're fantastic people, don't get me wrong, but...'* What he says suggests that he holds his employers in high esteem and the only obvious criticism against his employers in the passage quoted above is that they get *'confused'* or *'run out of steam'* or *'don't accept change very well'*. However, the subtext, what Harry tells of his experiences, reveals something more threatening. It seems as if Harry's perceptions of the organisation's values and commitment to him as an employee have shifted. It is almost as if Harry has to collude with the discriminatory practices he described, accepting short-term punishment (not providing a ramp or lift) for longer-term gain (*'they put in a lift for me in the new building'*). The first person reference here is interesting, suggesting perhaps that Harry perceived that the lift was only installed for his benefit, emphasising the special favour inherent in the phrase *'we'll make an exception for you'*. Repetition of *'big boss'* also seems to convey a sense of subordination, as if Harry had no choice but to accept this special status. Later in his account, Harry revealed that although the lift materialised, he was unable to access the room where the IT equipment was stored (*'I can't even get the wheelchair into the room'*), and elsewhere computer equipment was put out of his reach. He laughed this off; *'But it just means I can do less work (laughs)'* perhaps to deflect the researcher from probing further about what he felt about this situation.

So whilst Harry worked to bolster a preferred identity at work, powerful others undermined him by conferring special status, giving him help not offered to others, making sure that he knew that he was treated differently and by making life difficult in a very practical sense. Harry's long working hours take on another meaning when viewed in this context. Perhaps he felt he had no choice in this professional domain but to work long hours and to conform as a model employee; *'well I took it and just went with it.'*

DeJordy (2008) argued (with referenced to stigma in the work place) that organisations, through developing relationships with employees over time, carry expectations about how these relationships should develop. In this sense, Harry's working self-concept (Markus and Nurius, 1986) or his preferred identity, what he valued most and what was at stake at work, appeared both threatened and compromised by the experiences he described, and the expectations embedded in the relationship he had developed with his employer. Therefore, Harry might accept what would be intolerable outside the workplace because it enabled him to hold onto what mattered most; an identity as a *'normal bloke in a wheelchair'* (with a full time job). The workplace could therefore be seen for Harry as a particular public domain where compromises and discrimination had to be accepted in order to sustain a preferred sense of self.

## **7.7 Summary**

Coleman, (1986) argued that stereotyping discounts individuality by placing people into categories which instantly devalues them. Jim, Stella, Susan, Julia and Harry resisted this sort of out-grouping and all participants identified in Table 7.1 (p145) took steps to reduce the impact of stigma, and to challenge Goffman's (1963) concept of stigma as "master status". The analysis offered here supports other work (Scott and Miller, 1986; Miller and Kaiser, 2001; Oyserman and Swim, 2001; Shih, 2004; Major and O'Brien, 2005) which suggests that responses to stigma are multi-faceted, dynamic, situation-specific and interact with other dimensions of living with a progressive long term condition in both time and place.

Four participants expressed little or no concern about stigma (Graham, Scott, Joan and Ted). Many facets of their lifeworlds may have created or reflected such positive attitudes towards the social self. Certainly, basic sociodemographic variables such as gender and age appeared unrelated to the experience of stigma (see appendix N) with three of the eight male participants not describing experiences of stigma and one of the four women. Stigma was described by participants across the whole age range of those interviewed (see appendix N). Complex facets of the lifeworld such as employment

context, and the influence of certain powerful others in their social contexts, may have been far more influential. For example, accounting for divergent experiences, Ted, who also worked, did not report stigma. Ted's work environment, a large financial services corporation, may enact anti-discrimination policies more effectively and may have better staff training compared to the smaller firm employing Harry, who did describe stigma. Also as a larger company, Ted's firm may have employed more disabled people who had a stronger collective voice than perhaps Harry's solitary voice. Ted's senior position may also have conferred some protection from the discrediting behaviour of others. Joan had retired before her symptoms developed and at the time of the interview lived in her own flat in a retirement complex. Although Joan compared herself unfavourably with older and more able others in terms of her physical capacity, it seemed that her particular social context, where people might be expected to need help or to use walking aids, may also have created a less stigmatising environment. Graham and Scott were not working at the time of the interview and this may have influenced the contexts they drew upon during the discussion. As they were interviewed together it could be suggested that this created an uncomfortable situation where difficult issues like stigma could not be addressed. However, both participants recounted what might be considered distressing and painful experiences during the interview that would refute this theory. Also, unlike Joan and Ted, there was no evidence in the accounts to suggest that either Scott or Graham lived in particularly favourable circumstances which might protect them from stigmatising experiences. Therefore, whilst it is difficult to explore an absence, it seems that Ted's and Joan's social situation may have been different enough to account for their more positive experiences, whereas for Scott and Graham there were no clear differences to account for the lack of reference to stigma in their accounts.

## **7.8 Discussion**

An impression of this theme and its significance surfaced quite early on in the analytic process of individual accounts. Poignant incidents or particular decisions that distanced participants from the company of others clearly stood out as saying something important about the lived experience of progressive cerebellar ataxia. For example, Julia's decision to restrict her social behaviours so as not to '*cause offence*' had a powerful impact on the researcher during analysis and prompted further hermeneutic questions about the social implications of living with ataxia. Insights from more subtle or complex references to stigma were found in other accounts but only became apparent after working with the text over a longer period. Stella's description of walking in public (*'If I*

*think people are watching me I just freeze and my legs won't work*'), is perhaps another good example. Here, insight about problematic public appearance surfaced only after working through the researcher's initial biomedical assumptions about Stella's problems with walking.

The findings reported in this chapter are new with respect to enriching the understanding of the lived experience of progressive cerebellar ataxia and yet resonate with other studies of people living with movement disorders such as Parkinson's disease (Bramley and Eatough, 2008; Nijhof, 1995) and multiple sclerosis (Grytten and Måseide, 2005, 2006; Toombs, 1995) as well as aligned conditions such as Tourette syndrome (Davis et al.2004). However, these findings are the first to detail stigmatising experiences as described by people living with ataxia and to particularise experiences across a number of social situations. Participants' accounts revealed a complex interaction between stigma, identity and existential concerns which emphasised the embedded and contextualised nature of their lived experience. These findings therefore also reinforce the views of several authors who stressed the importance of closely studying stigma from the perspective of stigmatised individuals (Miller and Kaiser, 2001; Keusch et al.2006; Kleinman and Hall-Clifford, 2009).

The findings reported here connect with those of Boutté (1987) who conducted the only other study to explore stigma among people living with Machado-Joseph disease (SCA3). As discussed in chapter 3, Boutté (1987) interviewed key informants in two distinct cultural settings; a small island in the Azores and an area of California known to have a high immigrant population of people from the Azores. Both cultural groups reported stigmatising attitudes and behaviours directed towards individuals with "The Stumbling Disease". American participants reported stigmatising behaviours that were similar to participants in the present study, but particularly emphasised the stereotyping and social labelling concerned with apparent intoxication (with alcohol or drugs). However, the ways in which the stigma was mitigated differed in two ways from the present findings. Firstly, interviewees in America perceived so called 'stigma symbols' (Goffman, 1963:114) such as walking sticks as beneficial rather than stigmatising because they worked to confirm a preferred disabled identity rather than a discredited drunk identity. Secondly, in encounters with others, people with ataxia described themselves as having a different neurological condition, such as MS, to resist the 'tribal stigma' described by Goffman (1963:14) that attends Machado-Joseph disease. By contrast, key informants in the Azores identified stigmatising behaviours which were far removed from those reported by the participants in the present study. This was because

public intoxication was not a stigmatised category in Azorean culture and also because there was a well-established folk model of the condition which differed from the UK and US context which was no less diminishing, and was in fact deeply discriminatory. Although Boutté conducted her study over 25 years ago, this cross-cultural comparison helps to illustrate that the findings of the present study may be highly location- and culture- specific.

The understanding of stigma discussed in this chapter is drawn from intense idiographic analysis of individual accounts. This analysis does not intend to play down the influence of external oppressive forces or to portray the participants in this study as helpless or passive victims, or to illustrate the stigmatising experiences discussed in this chapter as simply a “personal tragedy” (Scambler, 2006). It was also not the intention of this analysis to create a stigmatised status or stereotype such as “disordered walking” or “disrupted embodiment” which may have worked to irrevocably label the participants in this study and to situate the stigma within the individual. Dear et al (1997) suggested that they knew of no terminology that was non-stigmatising when discussing disability. A pragmatic decision was therefore taken to use words that best described the phenomenon of interest whilst focussing on getting to grips with understanding the participants’ experiential world. In keeping with Yang et al (2007:1532), what seemed to matter most in the participants’ ‘lived engagements’ was the desire to be understood on their own terms and to preserve an acceptable and valued sense of self that was not defined by ataxia.

The fundamental power of a dominant group who make individuals feel diminished and devalued was realised in the narratives of the participants in this study. Powerful others (family members, Julia’s son and Susan’s daughter-in-law, work colleagues and managers as well as total strangers) were encountered in the intersubjective spaces of everyday activity and everyday environments. The behaviours adopted and described by participants in response to these experiences resonated with Goffman’s (1963) ideas about passing and covering, and Scambler’s (1998) concept of felt stigma; surveillance by the other (the stare or gaze) and self-surveillance or internalised oppression. These conceptions have been subsequently critiqued by authors writing from the perspective of the social model of disability (e.g. Reeve, 2002; Scambler, 2004; Thomas, 2010) for focussing on the individual and for not identifying the broader psycho-emotional dimension of disablism within which these behaviours operate and come into being.

Reeve (2002), for example, argued that individuals who respond to stigma by passing or covering, struggle to challenge the underlying disablism because it operates at a

subconscious level. In this context, passing or covering and self-surveillance are seen as a form of disability denial in the sense that these behaviours unwittingly “buy into” the hegemony of established social “norms”. Reeve (2002:503) further argued that ‘coming out’ as a disabled person and embracing a positive disabled identity would help to mitigate stigma by overcoming internalised oppression. However, Jim’s experiences, and those of the other participants discussed in this chapter, would suggest that adopting behaviours that resist psycho-emotional disablism is not a straight forward or pain free process.

Jim, for example, was the only participant who had actively engaged in the disability movement and he drew on this discourse in his narrative. Using arguments familiar to disability activists, Jim talked about reframing his sense of self and at least claimed a positive disabled identity. However, the idiographic analysis demonstrated that this positive sense of self was by no means secure. Jim’s reconstructed identity was in flux throughout his account and shifted with respect to his particular circumstances and existential concerns. Therefore Jim’s experiences would suggest that simply adopting or becoming familiar with the disability movement might not automatically secure protection against stigma, or re-frame an individual’s sense of self in a permanent way. Jim reported adopting both passing and covering behaviours at critical periods in his life, and still felt hurt and angered by what he assumed were pejorative responses to his disordered walking. Jim’s account therefore suggested that stressful experiences may disrupt the capacity to retain a sense of agency and autonomy, and to preserve a positive sense of self despite an awareness of the emancipatory philosophy embedded in the aspirations of the disability movement. In this respect, Scambler’s (1998) and Goffman’s (1963) ideas about stigma and the behavioural responses adopted to cope with the effects remain valid but, as argued by authors in the field of disability studies, should be understood not simply at the level of the individual but also within the larger contexts of the social oppression paradigm.

## **7.9 Conclusion**

The analysis presented in this chapter cautiously points towards an understanding that living with progressive cerebellar ataxia may, for some individuals, involve a problematic disclosure of the self and “socially incompetent behaviours” which echo the experiences and concerns of people living with other neurological conditions. For some people these experiences may take on a particular significance and meaning at times of transition (e.g. periods of deterioration). Forging a positive social identity at work also seemed to

add to the burden of living with ataxia. Further, the analysis revealed that people with ataxia may engage in behaviours designed to resist the negative consequences of ataxia and to preserve a more satisfactory sense of self. For some, these behaviours had deleterious effects in terms of reducing activities and reinforcing social stereotypes whilst for others, positive and affirming behaviours were difficult to sustain in the midst of looming existential crises. These findings were revealing because even though the behaviours and strategies were not uncomplicated in themselves, they were also, at times, wrapped up with efforts to contain and protect the self from the worrying concerns of living with a progressive long term condition. In this respect, the findings presented and discussed in this chapter suggest that ataxia should not be understood as “simply” a physical disorder. It should (in similar ways to Parkinson’s disease) be understood as a located illness (Nijhof, 1995) situated, experienced and managed in the inter-subjective spaces and places that formulate an individual’s local social world, where, according to Sartre, ‘one’s sense of one’s self is at stake’ (Moran, 2000:355).

## Chapter 8

### Super-ordinate Theme 3

***'The cerebellum should be a tight cauliflower and mine was two sticks of celery'***  
***(Julia)***

**Description: Lifeworld meets biomedicine: a complex juxtaposition**

#### 8.1 Introduction

This super-ordinate theme describes the participants' involvement in a disease-centric world; it portrays the meeting of the lifeworld with the world of biomedicine. This theme intends to demonstrate that for participants in this study, these worlds are simply juxtaposed. They come alongside but the biomedical world, in trying to overcome the distinct horizons of its own perspectives, seems at best to achieve a naïve assimilation of the participants' world and at worst a somewhat careless disregard. The extract used in the title of this theme refers to the analogy employed by medical practitioners to explain the results of Julia's MRI scan. Although stripped of context, this short phrase points towards the difficulty participants recounted in making sense of biomedical information. Julia was left nonplussed by this description. It perhaps conveyed a worrying picture of the cerebellum unfurling, but the real meaning of this and the implications for Julia, what this meant for her in her world, remained hidden and uncertain. The lay terminology could be seen as an attempt to create an intersection of meaning between the biomedical world and Julia's life world, similar to overlapping circles in a Venn diagram or Gadamer's 'fusion of horizons' of understanding (2004 [1975]:305) but the intended meaning remained hidden and left Julia more rather than less confused about what was happening to her.

Two subthemes convey the overarching theme in detail. The first subtheme draws attention to the participants' experience of testing and diagnosis. The participants described a decontextualised self, where healthcare professionals appeared to see them purely in terms of examinations, assessments, results and ultimately, if possible, diagnosis. This subtheme also captures the discrediting experiences that, for some, accompanied this process, as well as the uncertainty and tortuous nature of the journey into and through this particular world.

The second subtheme identifies the genetic component of the progressive ataxias as an issue for participants in this study. The majority of participants alluded to or directly addressed existential concerns about genetic inheritance and transmission. Participants,

on the whole, did not seem to make a clear distinction between diagnostic testing and genetic testing. Some participants also voiced reservations about the value of genetic testing for a condition where there is no cure or effective treatment. This subject was not an intentional focus of the main study and is worthy of deeper investigation in its own right, however, it is perhaps not surprising that participants' narratives in some way attended to a topic that, for most, carried a heavy significance.

Whilst the description of this master theme appears linear (tracing a path from initial consultations, testing, through to diagnosis), the participants described a rather more complex and iterative involvement with the world of biomedicine. The majority of accounts pointed towards the need to establish and maintain on-going relationships with healthcare professionals which operated almost exclusively within a biomedical framework. Participants described, for example, actively working to sustain partnerships often at considerable personal cost, in order to gain valued information and resources such as further diagnostic tests but also advice about how to best manage their condition. The majority of participants ( $n = 9$ ) portrayed an uneasy dependency on healthcare practitioners and through interpreting their accounts, the researcher gained glimpses of a complex paradox. Investigations and consultations were recounted as bewildering, and at times humiliating or frustrating experiences. At the end of these encounters participants reported feeling stuck, no further forward in understanding or making sense of their condition. At the same time they felt compelled to revisit this world and to seek further testing or advice. The following analysis and later discussion depicts this complex relationship which seemed to form an important cornerstone of the lived experience of the majority of participants.

Quotations from the majority of participants ( $n = 9$ ) have been used to illustrate the theme and to demonstrate the extent of the shared experiences. Shorter extracts, in the text or accompanying tables, support the primary quotations. Divergent experiences and interpretations have been indicated.

## **8.2 Subtheme 1**

***'I go and see the neurologist and I get another adjective, but I don't actually get a definitive answer' (Graham)***

### **Description: Making sense of ataxia through a medicalised lens**

This subtheme focuses on a world of diagnostic tests, medical terminology, examinations and assessments as understood and interpreted by participants in this

study. It describes and discusses the participants' initial and continuing search for information, certainty and meaning.

Nine participants either had a “working” diagnosis or did not have a more definitive diagnosis beyond idiopathic cerebellar ataxia (type unspecified) or cerebellar degeneration. Three had concrete diagnoses, Hugh and Julia (SCA6), and Harry (Friedreich’s ataxia). Table 8.1 shows that the majority of participants (n = 9) had lived with symptoms of ataxia for many years before receiving either a provisional or firm diagnosis. For the majority of participants, uncertainty about what was wrong and particularly what this might mean was knitted into their lifeworld and formed a powerful back drop for much of their narratives. This sort of uncertainty was a commonly reported experience, regardless of whether the path to diagnosis was relatively smooth or, more often, complicated and prolonged.

**Table 8.1 The Tortuous Path Toward Diagnosis (n = 9)**

<b>Participant</b>	<b>Narrative of the Path to Diagnosis (interviewed in 2007)</b>
Bill	1985 referred to neurologist, 1994 diagnosed with cerebellar ataxia, type unknown, pursuing further investigations at time of interview
Toby	Symptoms for many years, 2000 referred to neurologist, 2003 diagnosed with cerebellar ataxia, type unknown, no further investigations, diagnosed 'idiopathic'
Joan	1999 referred to neurologist, 2003 working diagnosis of episodic ataxia, investigations on-going
Harry	Childhood onset, diagnosed with Friedreich’s ataxia in his early 30s
Susan	Uncertain date of diagnosis, diagnosed cerebellar degeneration, pursuing further investigations
Stella	1996 diagnosed with cerebellar ataxia, type unknown, pursuing further investigations
Hugh	10 years from referral to diagnosis with SCA6, genetic details uncertain, not pursuing further investigations
Scott	2001 symptom onset, diagnosed cerebellar ataxia (specific date not known), type unknown, investigations on-going
Graham	Always had symptoms, 1994 diagnosed with cerebellar ataxia, type unknown, investigations on-going

With reference to Table 8.1 and to account for the divergent experience of the three remaining participants, Ted, through private healthcare, was referred to a consultant without delay and received a diagnosis of late onset cerebellar ataxia within twelve months of onset; Jim did not talk about the details of the events leading up to his diagnosis but as other members of his family had the same condition, it is possible that as a result, Jim felt that his diagnosis was uncomplicated. Julia was diagnosed relatively quickly, nonetheless the process was not described as unproblematic. Her experiences

mirrored to some extent those of others and are discussed below. Most narratives (n = 10) communicated a deep sense of frustration and abandonment with what was perceived as a lack of knowledge and understanding from healthcare professionals (Table 8.2).

**Table 8.2 Frustration and Abandonment: An Experience of Biomedicine (n = 10)**

Participant	Extract	Page: line number
Harry	<i>'If you keep your head down they won't try. They won't offer any help'</i>	23:33
Stella	<i>'So much ignorance about this particular thing'</i>	2:23
Stella	<i>'They think it could be this but they don't know. [...] They don't know what else to do with me really'</i>	3:9
Ted	<i>'Not had any advice, it's just sorting it out for ourselves'</i>	3:6
Toby	<i>'[GP said] 'It's no good coming to me [...] I don't know anything about it''</i>	25:21
Scott	<i>'They haven't got a clue'</i>	16:27
Jim	<i>'Nobody seemed to care about it or consider it'</i>	5:22
Jim	<i>'There was no support, no nothing'</i>	7:9
Bill	<i>'Here we go again someone else has never heard of it'</i>	11:5
Bill	<i>'We just paddle our own canoe'</i>	9:2
Susan	<i>'If they say 'I don't want to see you anymore', I say that I am entitled to see you again'</i>	5:27
Graham	<i>'With the neurology department, it's quite ... it seems to me I have to justify actually being there'</i>	15:17
Graham	<i>'The neurology department aren't really ... don't really give me the impression they really know what ataxia is'</i>	15:35
Hugh	<i>'I wasn't getting much help'</i>	2:29

Julia's journey to diagnosis provided a way into understanding participants' encounters with biomedicine and is offered here as an introduction to this subtheme. Julia spoke about several problematic consultations with her GP which involved repeated diagnoses of labyrinthitis and reassurance that there was *'nothing to worry about'*. The experience was portrayed as incredibly distressing; *'I thought I was going mad'*. She explained; *'I kept being dizzy. And kept being diagnosed with labyrinthitis [...] my head was a fishbowl with the water slopping and I'd have to stand still until the water stopped'*. The repetition of *'kept'*, and the image of Julia's head actually becoming a fishbowl with her eyes and her brain sloshing about inside, communicated a strong sense of bewilderment

and spoke for the precarious position she seemed to find herself in. The eventual diagnosis, appeared to re-anchor Julia by calming her existential turmoil; *'although there was nothing they could do, the fact that I knew what was happening relieved a lot of anxiety'*.

Two other participants (Toby and Joan) recounted similar experiences to those described by Julia where they considered that specialist referral was only achieved through their own determined persistence. The following extract is taken from Toby's account:

*Toby: 'I noticed that my knees were like jelly, like trembling. I went to my doctor's and asked about this, but never really got any explanation [...] I kept going to my GP [and explained that] just occasionally I'd overbalance. So I asked my GP if he could explain this and he gave me tablets for vertigo. I took them for a week and they didn't make any difference whatsoever. [...] So this continued over the next seven years ... and the symptoms of that overbalancing got worse, and the last time I went on my own [...] I went and I said 'I'm sure this can't be normal'. He did neurological tests [...] and couldn't come up with any explanation. Yeah?'*

*Interviewer: 'Yeah.'*

*Toby: 'So a year on, I'd got worse than that and I asked my wife to come with me to the doctor's to give some credence to my story. Because it was as if the doctor didn't believe or wasn't listening to what I was trying to tell him. I noticed when my feet were direct together it was worse, as if my body was wide at the top, like a pivot yeah? [...] He tested me and he subsequently said 'You seem quite bad', he says 'you ought to have come before'. And my wife said 'But he's been coming for the last seven years saying something's not right'.*

This passage illuminates Toby's experiences in two important ways. Firstly, it is possible to picture Toby here, doggedly visiting the surgery, patiently describing his problems from his direct experience ('jelly', 'trembling', 'overbalance', 'like a pivot'). Toby's journey towards diagnosis was portrayed as an arduous quest replete with seemingly insurmountable obstacles which blocked his path. He repeatedly asked for an explanation of what was happening to him ('I went to my doctor's', 'I kept going to my GP', 'this continued over the next seven years'). From Toby's perspective, the GP resisted engaging in meaningful dialogue – *'[he] wasn't listening'* – and as such declined to enter the frame of reference or horizon of experience that was most meaningful to

Toby. Not only this but from Toby's perspective the GP might have doubted that there was something "really" wrong (*'as if the doctor didn't believe', [I took my wife along to] give some credence to my story'*).

Secondly, the GP seemed firmly situated in the biomedical world, administering *'neurological tests'* but not really listening to Toby. It might be assumed here (at least from Toby's perspective) that the GP's knowledge was constructed using the objective body as source, as it was measured and observed, and that these data were prioritised over and above that of Toby's previously discounted subjective account: *'He tested me and he subsequently said 'You seem quite bad'.*' Here, it seems that Toby understood that it was the data that took precedence and was attended to, leaving him with the impression that his story, the personal experience that he took to the surgery, as opposed to his "data", was overlooked or even disbelieved.

This brief vignette resonates with Julia's experiences but also captures a phenomenon conceptualised as the reluctance of one communication partner to move from a preferred (biomedical) lifeworld into the lifeworld of another, the patient. In this situation, objective data (test results) are "real" and are prioritised over and above the less tangible, distinctly human and personally situated story of the patient. Characterised by an unwillingness to engage with patients in and on their own terms, this type of communication style has been identified as a particular feature of medical consultations for people presenting with long term physical symptoms (Barry et al. 2001).

Joan recounted similar difficulties to those described by Toby and Julia. Joan experienced fluctuating symptoms and described going to great lengths to *'create an episode'* for her doctors to observe. With the help of her family, she had made a digital recording of herself which her doctor had been unable to watch. Therefore neither her consultant nor her GP had actually seen her *'malfunction'* (Joan). At first Joan's GP diagnosed *'normal ageing process'*, which made her *'a bit angry'*. However, Joan persisted and was referred to a specialist who eventually diagnosed probable episodic ataxia. As with Julia, giving it a name, acknowledging that there "really" was something wrong, provided Joan with some relief from her frustration and distress. She explained:

*'Symptoms have become so spasmodic and erratic; I have felt such a bore and such a fraud, especially in the hospital. [...] I now know that I can try to explain how bad it actually is, because when I saw [my consultant] I got this not firm diagnosis but recognition perhaps.'*

Without a diagnosis Joan felt *'a fraud'*. Her symptoms were unpredictable and, from the perspective of healthcare professionals, unobservable. Living without a diagnosis, understanding that others might consider not only her account of her illness as a sham, but by implication perhaps other parts of her life too, Joan was effectively silenced, unable to speak of her very real suffering. A diagnosis, albeit provisional, seemed to confer veracity and plausibility (*'recognition'*), in other words it confirmed to Joan and told others that the problem was "real". An official label therefore gave Joan permission to talk (*'I now know that I can try to explain how bad it actually is'*) without risking censure or disbelief. However, Joan suspected that her GP continued to doubt the working diagnosis; *'he thinks there's no such thing as ataxia wrong with me'* because he had never seen Joan *'malfunction'*.

Although Julia's type of ataxia is well described in the literature, it is unlikely that her GP would have been familiar with the progressive ataxias. Also given that she had no known family history and that it only emerged later that her brother had the same symptoms, the GP had little to work with and perhaps pragmatically opted for the more common diagnosis of labyrinthitis. Joan's and Toby's conditions were rather complicated; Joan's because of its episodic nature and Toby's because it may have been masked, at least at first, by a completely separate illness. Given the relative rarity of cerebellar ataxia, it is not surprising that the participants' GPs were perhaps slow to request a specialist opinion. Looking at these accounts from a realist perspective may indeed suggest some shortcomings in the way in which GPs responded to these participants' problems. Nonetheless, from the participants' accounts, it seemed that GPs resisted entering the lifeworld of these three participants, leaving them with the feeling that they were disbelieved or at least not taken seriously. Making an attempt to understand the participants' subjective experiences may have done much to alleviate what was (and still was, at least for Joan) a prolonged and distressing part of their lives.

The above accounts have drawn attention to the difficult process described by three participants in accessing specialist health care, in particular referral to medical consultants. It also provided insight into the stress attached to these discrediting encounters and the uncertainty that accompanied living with an undiagnosed condition. The next section of this subtheme focuses on the participants' accounts of their experiences once they were referred to specialist services. As the following exchange shows, this was not necessarily straight forward and was often just the beginning of a long and frustrating process which carried with it a heavy psychological toll. The outcome of these encounters (usually a provisional diagnosis) often did little to alleviate

the uncertainty and did not necessarily provide the information or understanding that participants seemed to seek. A lengthy extract from Stella's account perhaps captured this most clearly:

*Stella: 'I saw [my first consultant] for two or three years and then he discharged me. I moved from [one consultant] to the [next] and again I felt that I needed to be involved with the specialist so I went to my GP again, he referred me to the local hospital and again I was with that specialist for about three years. He eventually ... the first diagnosis was ... I can't pronounce this ... spironella ... the first ... they didn't know what type of ataxia it was [...] The second diagnosis, he felt it could be [something else] and from there I saw him for a few years and then he discharged me. So again, after a lapse of time, and reading various information which stated that you should never be discharged because of new things coming up, I went back to my GP and got him to [re-] refer me. So at the moment I'm now with [this] consultant. He had very little time with me because he was very busy, so you know I didn't have much time with him this time.'*

*Researcher: 'How did you feel when those first consultants discharged you?'*

*Stella: 'Um ... a bit helpless really. Um ... you're floundering about in the dark and you haven't any contact, you know to sort of help you. It's a very difficult thing to describe really because you find that there's so much ignorance about this particular thing and it's just one long battle. Sorry I'm getting ... [tearful].'*

[After a break]

*Stella: 'Oh dear me, yes. So ... that's the story really. So yes, I did feel let down I suppose when the consultant said, you know, 'go away'. And the first consultant ... you see the second consultant, then this [other] thing had come up ...'*

*Researcher: 'Yeah.'*

*Stella: '... so if I hadn't have pushed myself forward to see somebody again, I wouldn't have known about that.'*

With echoes of Julia's, Toby's and Joan's earlier accounts, Stella related a moving story of single-minded determination in the face of painful and repeated rejection; she also touched on several threads common to the other participants' accounts.

Firstly, Stella projected two contrasting and intertwined images in the above extract. She described feelings of vulnerability ('*floundering about in the dark*', '*helpless*') and isolation ('*you haven't any contact*'); she seemed powerless and downtrodden by events

outside her control. The reference to the *'dark'* added a sense of fear, desperation and anxiety to this scene. Revisiting these devastating events eventually overwhelmed her. The pauses and the switch in subject from *'I'* to *'you'* when Stella talked about her most painful experiences may have been used to deflect further questions. Within this narrative Stella also drew on metaphors of conflict (*'one long battle'*). Having armed herself with knowledge (*'reading various information which stated that you should never be discharged'*) and with great effort, she pitted herself into battle, *'pushed myself forward'*. It is possible through these images to almost visualise the strength of Stella's resolve as a new self; a kind of heroic warrior contrasting strongly with the image of her formerly diminished self. However, the echo of this former self still reverberated through this passage serving as a reminder that the strong Stella might be fragile and prey to further assault. This interpretation is cautiously suggested because it is grounded in Stella's use of the present tense; *'there's so much ignorance about this particular thing and it's just one long battle'*; in other words, there still is so much ignorance and it still is one long battle.

Stepping back from the emotional impact of Stella's words, it is also possible to attend to a broader subtext in this narrative. As Butler (2002:45) explained with reference to Foucault, language 'expresses and enacts the authority of those who are empowered to use it'. Stella is *'discharged'* three times. Discharged is a word used by healthcare professionals, the military and the judiciary, people who traditionally hold a position of high status. Stella seemed to interpret this to mean that she was dismissed with the full weight of a higher authority, effectively told to *'go away'*. Medical specialists were portrayed in Stella's account as powerful gatekeepers who frustrated her attempts to seek knowledge and understanding, and ultimately to make some sense of her condition. The following quotation lends weight to this interpretation. Stella had asked to be copied into the correspondence between her GP and consultant but rather than offering illumination, the letters were a source of further frustration:

*Stella: '... got a letter ... here we are. Ah, neurological examination ... there, I can't say that ... 'reveals broken pursuit ... but no evidence of nystagmus'. So broken pursuit is my eyes move quicker, do they? Or they flash about or something? [...] And then 'she has well preserved reflexes and no evidence of any sensory disturbance to suggest a peripheral neuropathy' [laughs]. Do you understand that?'*

In this extract Stella was trying to understand some complex medical terms, she read out sections, asking for confirmation of her sense-making but the language remained inaccessible without specialist interpretation. Understanding, empowerment and

partnership was not facilitated or developed here, Stella summarised her situation, as she saw it, as follows:

*Stella: 'You know it's very hard getting explanations from consultants isn't it? They have all the knowledge but sometimes they don't impart it to you. Whether or not they think you can't understand it I don't know. Perhaps they feel it's not important but I think it is. If you understand the functions and how you work, I think that's very important. And me being me, I like to know all the ins and outs, you see, and how it works.'*

For Stella, consultants *'have all the knowledge but sometimes don't impart it'*. As Stella sees it, their privileged position means that information is within their gift but they chose not to share in a way that was meaningful for Stella. She felt cut off from a source of valued information (*'I like to know all the ins and outs'*) through being discharged or through not having the opportunity to enter into a meaningful discussion with her new consultant (because he was *'very busy'*) or through receiving correspondence that was not accessible to a lay reader. The phrase *'me being me'* emphasised Stella's resilience and her continuing effort to assert and preserve her sense of self; her attempts to actively participate in her healthcare, to resist the constraints of language, privilege and practice, and ultimately to make some sense of her situation. However, like other participants, she seemed to be consistently frustrated in this undertaking. Two further passages from Graham's account lend support to the development of this theme:

*Graham: 'I seem to be diagnosed with a string of adjectives describing what my condition is but not actually pinning it down. So for example, chronic is quite a worrying thing to me. But it means ... it's got a different meaning from the general chronic words. So that worried me for a while and I didn't really ... [...] But the doctors call it idiopathic, which means they don't know where it came from [laughs]. They call it genetic, well anything's genetic, that's not clearly defined either. They call it inherited. Okay are you covering your bases or what? Inherited, genetic ... [...] I go and see a neurologist and I get another adjective but I don't actually get a definitive answer.'*

Graham's experiences with his consultant seemed to reflect Stella's; without expert interpretation, the words either held no meaning or carried a significance that through being unclear caused concern, like chronic: *'it's got a different meaning from the general chronic words. So that worried me for a while and I didn't really...'* The way this sentence peters out seems to communicate a sense of disorientation, rather than anchoring him, each new diagnostic category seemed to threaten to set him further adrift. For Graham, the consultant's explanations were troubling rather than

enlightening, not only because they compounded his anxiety and frustration but also because he seemed to have an expectation that his consultant should be able to '*pin it down*'. Graham was looking for answers and in response his consultant gave him what Graham saw as meaningless words that concealed a lack of knowledge; '*the doctors call it idiopathic, which means they don't know where it came from [laughs]*'. Both Graham and his doctors seemed to be caught up in a traditional medical discourse that is unable to accommodate a condition for which diagnosis (and prognosis) is problematic and complex. Above all, however, Graham seemed to be looking for meaning, a way of understanding his condition in his own terms:

*Graham: 'It doesn't help that I don't know which pigeon hole to put myself in if you like. It's just, I guess, it's more of a psychological aspect to being ... have a medical condition. It's not quite knowing where to pin it down, what caused it you know, who's to blame if you like.'*

In the absence of a clear diagnosis, Graham seems uncertain about his place in the world; not only in the sense of the present ('*which pigeon hole to put myself in*') but also in the sense of the past ('*what caused it you know, who's to blame*'), an oblique reference perhaps to the problematic and worrying adjectives, '*inherited, genetic ...*' appended to a growing list of diagnostic jargon. In addition to the evident frustration, Graham's sense of self seemed uncertain, not knowing what was wrong or what caused it conveyed a kind of psychological homelessness. There are parallels here with Stella's description of herself as '*floundering about in the dark*'; a sense of loss of self or disorientation that is psychologically hard to bear. These accounts suggested that there was very little intersection of meaning between the lifeworlds of the participants and the biomedical world of their healthcare specialists. Instead, encounters with healthcare professionals seem to have deepened rather than alleviated the participants' uncertainty and existential anxieties.

Graham's and Stella's account resonated with themes that featured in the majority of participants' narratives, notably the on-going search for personally relevant information and a more specific diagnosis. This quest manifested itself in extensive testing which, for most, failed to provide them with the concrete or meaningful answers they sought (see Table 8.3 pp. 180).

**Table 8.3 A Lifeworld of Testing and On-going Uncertainty (n = 9)**

Participant	Extract	Page: line number
Bill	<i>'Tested for SCA 1, 3, 4, 6, DPLA and Friedreich's ataxia, they were negative'</i>	2:30
Jim	<i>'It's a type of cerebellar but there's no SCA number'</i>	1:16
Susan	<i>'I've had every test imaginable [...] I'm not even sure what they're testing for [...] Nothing has proved positive'</i>	5:33
Susan	<i>'They can't find any specific one that applies to me'</i>	5:13
Stella	<i>'They can't diagnose which ataxia I've got'</i>	3:4
Hugh	<i>'It took them over 10 years to find out what was wrong'</i>	1:5
Scott	<i>'It's been a series of tests – cut that out, cut that out, so you get to a point where they haven't got a clue'</i>	16:26
Scott	<i>'All they can do is take blood tests, check your DNA profile'</i>	16:28
Graham	<i>'The doctors call it idiopathic [...] they don't know where it came from'</i>	17:6
Joan	<i>'Nothing spooky came up and no diagnosis'</i>	6:19
Toby	<i>'I'm not sure [which type]. It's idiopathic, which means no known cause'</i>	1:21

Furthermore, as a result of on-going investigations, it was not uncommon to find that provisional diagnoses were amended either radically by suggestions of a completely different condition, especially in the early stages of specialist referral, or in a minor way that offered very little additional information and which paradoxically rendered this new “information” meaningless. For example, still under the umbrella of cerebellar ataxia, Stella's diagnosis had been revised over the years; she had been given two previous diagnoses and had just found out about the possibility of a third. Four participants described undergoing comparable experiences; Bill was told originally that he *'probably had MS'*, Joan was told, *'normal ageing process'*, *'chronic fatigue and then motor disorder'*, Susan was *'diagnosed with lupus'* before undergoing orthopaedic surgery for a *'balance problem'* and, via further visits to physiotherapy and her GP, was eventually diagnosed with *'cerebellar degeneration'*.

Graham, like Stella, was diagnosed with cerebellar ataxia and as noted above also found that his diagnosis was subject to frequent revision:

*Graham: 'I go and see the neurologist and I get another adjective, but I don't actually get a definitive answer. Like ataxia [Ataxia UK] says there's these SCAs you know 1 to 13 or whatever, it is – I haven't got one of those types – I haven't got Friedreich's ataxia, I've just got some other form of ataxia which is as I understand it a generic term for people with balance problems. So it's not clearly defined.'*

In medical terms, the diagnosis of cerebellar ataxia not only involves the exclusion of conditions such as MS but also other conditions with similar symptoms such as cerebellar tumours (Abele et al. 2002). These conditions have a widely acknowledged and sinister reputation, Joan referred to them collectively as 'spooky' and Ted as 'nasty'. Once these conditions have been discounted, diagnostic refinement is undertaken via a process of elimination which entails multiple testing for known types of the progressive ataxias. Most of these tests are negative (Wardle and Robertson, 2007; Finsterer, 2009; Klockgether, 2011) and even though a negative test may rule out some of the known ataxias it still leaves a large proportion of people living with ataxia without a firm diagnosis. A negative test would therefore seem to carry little meaning except to deepen the frustration already apparent in participants' accounts and to raise doubts about the specialists' expertise; *'you get to a point where they haven't got a clue'* (Scott). A further extract from Graham's account reinforces this point:

*Graham: 'You just sit there and you're waiting for someone to read your notes and they read your notes and they have five minutes, say 'How are you?' So you're getting that and then you don't get anything for 18 months or so. You think 'Well hang on a minute [...] how's that informing me, my situation?' [...] I have to keep informing them [the neurologists] all the time [...] people in the [local hospital] have said they might only see me and I might be the only person with ataxia they see, you know. Which is fine you know but it just seems to be a bit ... I don't know ... it doesn't feel like I'm getting much attention. It's difficult to explain. I don't really want a lot of invasive attention, but I just ... sorry ... I just think that without actually me pushing for things I won't actually get anywhere and I'm not really good at being pushy.'*

Graham seemed unsurprised that the neurologists lacked specialist knowledge about his condition. He also seemed annoyed at the little time he spent with the consultant and the process of having to continually repeat the same information, as if he was starting from scratch with every subsequent appointment. However, what seemed to come across most strongly in the above quotation was Graham's impression that the consultation was not geared towards his concerns (*how's that informing me, my*

*situation?*). Importantly it seemed that he felt as if he was failing to make any progress towards making sense of his particular circumstances (*'I won't actually get anywhere'*).

Graham appeared almost apologetic for expecting any sort of *'attention'* and he seemed to find it difficult to express exactly what it was he was looking for (*'I don't know', 'it's difficult to explain'*). In order to have his concerns or questions addressed Graham felt he needed to make a kind of special effort, to be *'pushy'*, but unlike Stella (*'I went back to my GP and got him to [re-] refer me'*) and Susan (*'I say, 'I'm entitled to see you again''*), he seemed unable to assert himself in this way. As he said later, he believed he had to *'justify'* his presence to the consultants (Table 8.2). Graham seemed to feel trapped in a circle of pointless consultations which perpetuated his sense of frustration. The pointlessness was reinforced by the apparent way in which the doctor's preparation for the encounter (reading the notes) and the social niceties (*'How are you?'*) seemed in his eyes to take up all the brief time of five minutes that he had been given. Furthermore these consultations did little to resolve his concerns, and feeling somewhat compromised for turning up to his appointment, even invalidated them.

Harry's and Hugh's accounts suggested that even a definitive diagnosis may not confer certainty. Hugh, for example, was diagnosed with SCA6 but his test results did not help him make sense of his condition in the longer term:

*Hugh: 'When I asked the doctor how many repeats there were on my defective gene he couldn't tell me, because the people who did the DNA testing just said 'enlarged', it didn't say how many repeats. The number of repeats can or virtually tell you how bad you're affected.'*

Hugh seemed to be referring here to the possibility that he may carry an unstable triplet repeat within his genetic profile. In this case, paternal transmission may lead to significantly reduced age of onset and a more severe clinical presentation in children who inherit the condition (Friedman, 2011). This might be what he was contemplating when he suggested that the *'number of repeats can or virtually tell you how bad you're affected.'*

Similarly for Harry, a diagnosis of Friedreich's ataxia was useful in terms of giving his condition a name; *'it was quite good because they actually told me that I'd got Friedreich's ataxia'* but it raised new concerns about associated conditions; *'They say you can get a heart murmur, you can have ... what's that thing where you drop dead? Where you heart just stops. One doctor described it to me.'* Therefore it seems that both

negative test results as well as a definitive diagnosis can both, in different ways, add to the existential uncertainties that seem to be part of the fabric of living with a progressive ataxia.

### **8.2.1 Summary**

These accounts support the understanding that the process of diagnosis for most participants was long, arduous and potentially never-ending. It often consisted of shuttling between consultants and GPs (who, from these accounts, seemed to operate entirely within the strict borders of the biomedical model) whilst trying to make sense of on-going uncertainty and frustration in the light of, at best, provisional diagnoses. Participants' sense making seemed to be obscured by health professionals' reliance on jargonistic language and disease-centric practice; a particular problem associated perhaps with a condition where diagnostics remain uncertain and for which there is no cure or treatment. Despite this dispiriting process, half the participants (n = 6) continued to seek out further testing. The following subtheme explores the participants' reasons for either pursuing further investigations or for bringing them to an end. Almost without exception (n = 11) the decision involved either oblique or overt reference to the genetic, inheritable characteristics of the progressive ataxias.

### **8.3 Subtheme 2**

#### ***'I think my brother's got it' (Hugh)***

##### **Description: Ataxia in the family**

Most participants did not dwell on the issue of inheritance in their accounts, perhaps reflecting that such topics were deeply personal and difficult to discuss with an unfamiliar person, particularly when the ground had not been prepared and some sort of concordance about the topic had not been agreed in advance. However, all participants, except Ted, made either a direct or indirect reference to genetic testing, family history or inheritance within their narratives. Ted was the exception possibly because, being relatively newly diagnosed, as well as being a new father, this may have been too sensitive a subject for him. Participants' references to the possibilities of genetic inheritance and transmission were intricately knitted into their involvement with diagnostics and the medical world, as well as their efforts to make sense of the contexts of their lives.

Participants recounted highly situated and context-dependent experiences that were difficult to group thematically without losing the particularities of each case. Whilst there was some degree of overlap, no single participant's experiences easily mapped onto those of another. However, careful analysis showed that the genetic component of the progressive ataxias could perhaps be best understood in temporal terms; participants projected back in time, sometimes with new insight, into their family history and/or projected forward in time with troubling anticipation for their children, grandchildren or siblings. For some participants, genetic considerations loomed large and fell within the immediacy of their existential concerns. For others, such concerns emerged as something that had been dealt with in the past but were nonetheless still powerful enough to surface in the context of the interview.

This discussion starts by returning to Graham and Stella, and then addresses the concerns of a number of participants to demonstrate the diverse ways in which this issue emerged and was understood. Further brief quotations from those participants who provided fleeting glimpses into this aspect of their lifeworld are presented in Table 8.4.

**Table 8.4 Fleeting References to Genetic or Hereditary Issues (n = 6)**

Participant	Extract	Page: line number
Bill	<i>'It would be useful [...] if I could say to my children ['It's this'] so that they could be without too much anxiety about what they might be doing for their potential offspring'</i>	1:37
Joan	<i>'Of course it is worrying because it's genetic, it's episodic'</i>	1:33
Julia	<i>'I told my brother about it [the MRI] because my father had something that we didn't ... it wasn't MS but it was something'</i>	15:6
Harry	<i>'My sister wanted kids and she didn't want the kids to get what I've got [so I had the gene test]. [...] It was quite good because they actually told me I'd got Friedreich's ataxia'</i>	23:18 /24:29
Toby	<i>'I know it's idiopathic, which means no known cause, not hereditary cerebellar ataxia'</i>	1:21
Scott	<i>'But to be able to prove that [I've got this particular ataxia] you got to prove that you haven't got genetic and all that'</i>	17:18
Susan	<i>'Some people need to know whether to have children, or whether they're passing on a faulty gene. But I've got children and grandchildren, so it's too late for me to make those considerations'</i>	6:18

As noted in subtheme 1, Graham seemed to be grappling with issues about his identity in the present (*'which pigeon hole to put myself in'*) whilst also perhaps understanding that a piece of the puzzle might be missing from his past, *'what caused it you know, who's to blame'*. Graham had been told that he had a genetic condition; *'They call it genetic, well anything's genetic, that's not clearly defined either. They call it inherited'*, and although he almost made light of it, he admitted that it was of *'psychological'* importance to establish some sort of certainty about his diagnosis. It seemed, for Graham, that a firm diagnosis, by enabling him to look with clarity into his past, may have been able to give him some sense of who he was in the present. For Graham, the genetic issues were just one of a number of pressing concerns about his condition and ultimately his sense of self.

In the reverse of Graham's situation, a piece of the puzzle from Stella's past had recently come to light which served to add to the confusion and uncertainty that she was already living through:

*Stella: 'Just a few days ago my sister said that my mother, on the death certificate, it was mentioned that she had cerebellar ataxia, which was an absolute bombshell to me because I'd spent ten years trying to find out whether it's hereditary or whether it's one of these other [...] I mean I knew she had bad balance but she always put it down to an inner ear problem. [...] And I thought she had never been followed up.'*

Stella's symptoms first emerged before her mother died, and therefore her mother may have been in a position to tell Stella about her condition. It is not clear why Stella's sister had only just told her about the death certificate, there may be many reasons. However, apart from the huge shock, as a daughter, reflecting back in time, Stella had to confront the possibility that her mother kept her diagnosis secret, whilst from that point forward, as a grandmother, she had to contemplate the profound implications that she could have known about this hereditary condition ten years earlier:

*Stella: 'I mean the main ... one of the main reasons for me following this up as well is for my children really [...] And whether or not they're going to be affected.'*

Stella had perhaps hoped that her condition was not hereditary. None of her siblings had, it seemed, been willing to be tested, so this newly-found piece of the puzzle from her past had become hugely significant not just for Stella but also presumably for the rest of her family. This knowledge (about her mother's condition) threw her previous diagnoses into question by firmly re-establishing the possibility that Stella had inherited

her ataxia from her mother. The uncovering of a family secret exposed Stella to a new set of bewildering and upsetting problems that perhaps confirmed her worst fears (*'I've spent ten years trying to find out whether it's hereditary'*). The potential implications for her children and grandchildren emanated from this news and seemed to intensify her sense of shock (*'absolute bombshell'*).

Stella and Hugh shared similar concerns about the risk of passing on a variant gene and feeling responsible for the lives of future generations. However, these accounts seemed to offer two highly situated responses towards these dilemmas. As noted above, Stella seemed very much orientated towards finding out what passing on an inheritable condition might mean for her children's lives, whereas Hugh was very clear that given the choice he would have opted to have artificial insemination:

*Hugh: 'My children, they've got a 50% chance of getting it, which is ... if I'd have got the diagnosis earlier, I wouldn't have had children, I would have had artificial insemination and then the children wouldn't have had the problem.'*

By saying that he would have chosen not to have children, Hugh perhaps revealed something significant about his perceptions of the quality of his own life and his assumptions about his children's future lives. One interpretation that could be offered about the quotation above is that Hugh assumed that his children would be at risk of having a life as bad as his life. In this sense by not bringing children into the world, Hugh may have been suggesting that his own life, at this time, was not a quality life. It is possible to understand from this extract that, in Hugh's eyes, his life is of such low quality that it was not a life he would wish on anyone else, least of all his own children.

Unable to change the past, Hugh had decided not to tell his young children of the possibility that they may have inherited the same condition; *'the children don't know that they could have it, we've kept it quiet.'* Here, Hugh explained his decision making by revisiting his past choices and validating them in light of the future. He seemed reluctant to burden his children with the facts of his diagnosis; *'they're kids, it's something they shouldn't know'*, he also had pragmatic concerns about the *'insurance and mortgages and all the rest of it'* and he questioned the utility of genetic testing for a condition for which there is no direct treatment or cure:

*Hugh: 'there isn't treatment for it, so there's no reason to tell them. If there was treatment and it could be helped then I would tell them. But there isn't any treatment so it's all a big disadvantage as soon as they know.'*

However, Hugh was also coming to the realisation that rather than protecting his children, his closely guarded secret may have stimulated some unintended consequences;

*Hugh (with reference to his daughter): 'She doesn't like what's happened to me, she doesn't understand it and she's angry about it, it's affecting her behaviour. [...] It seems to be hurting her quite a bit, just seeing the way I am.'*

Whilst Hugh freely offered this candid analysis, immediately afterwards he changed the subject, perhaps to put some psychological distance between him and this troubling portrait of his daughter's distress.

Hugh's family circumstances also reflected Stella's in one other important way; no one else in his family had been tested despite Hugh's suspicions that his brother had the same condition: *'I think my brother's got it'*. This certainly was not the case for the majority of the other participants. For example, although Jim agreed with Hugh about the lack of benefit from genetic testing (*'We've been offered genetic tests, but in simple terms unless they can identify the missing gene there's no point putting the kids through it'*), Jim's children had grown up in the full knowledge of their father's condition:

*Jim: 'They've basically been brought up with it [...] my brother and sister have both got it so ... they've been brought up not just by a parent with it, but within the sort of family.'*

Jim was very clear that for him, bringing his children up knowing about the condition was a benefit rather than a burden:

*Jim: 'I think that's a positive effect of living with somebody that's got an illness that if you're just open with them they don't see it as a problem, they just think 'well it's ok, just get on with it'.'*

Although not articulated as directly as Jim, from the context of their accounts it would seem that Bill, Joan, Julia and Harry also shared Jim's sentiment and did not hide their condition from either their immediate or extended family. Stella did not hide it either but, without reading too much into Stella's account, it seemed that, similar to Hugh's family, other members of her family were perhaps less well disposed to openly discussing the implications of her condition. Neither Graham nor Scott made a direct reference to members of their family. This might be because this was a joint interview and therefore too sensitive a topic for strangers to discuss with each other. Harry, on the other hand, was rather pressured into genetic testing because his sister wanted to start a family (see

Table 8.4). He dealt with this quite frankly in his interview and did not dwell on the implications for his potential future family. Again this may have been not only because he was talking to a stranger but also because Harry's girlfriend was an almost constant presence during the interview.

Susan was the only participant who seemed to be pursuing a diagnosis for purely altruistic reasons:

*Susan: 'Some people need to know whether to have children, or whether they're passing on a faulty gene. But I've got children and grandchildren, so it's too late for me to make those considerations. But I just want to do it for Ataxia because I support them ... Ataxia UK I mean.'*

However, as with some of the other participants this almost offhand reference to her children and grandchildren might belie more existential concerns that Susan was unwilling to visit in this interview. Similarly, Bill was also interested in supporting further genetic research but also perhaps slightly underplayed the significance and meaning of finding a definite diagnosis:

*'It would be useful [...] if I could say to my children [it's this] so that they could be without too much anxiety about what it is they might be doing for their potential offspring.'*

Here, Bill seemed to understate the significance of finding out about the potentially hereditary nature of his ataxia (*'it would be useful'*) and framed this with reference to his future grandchildren. However, pushing the interpretation, digging underneath this rhetoric by using a more questioning hermeneutic might uncover what might be hidden in this narrative, perhaps a deeper concern about what Bill might believe he has *already done* to his *own* children.

### **8.3.1 Summary**

Overall, the findings reported here suggest that, concerns about genetic inheritance and transmission seemed to form a persistent undercurrent in the lived experience of the majority of participants; an on-going concern that ebbed and flowed depending on the particular circumstances and contexts of participants' lives. Graham, Stella and Hugh, in particular, reported immediate and significant concerns, raising questions not simply about personal identity but also about family history and their hopes and fears for future generations.

## 8.4 Discussion

The majority of participants' accounts seemed to suggest that clinicians dismissed their search for meaning by interpreting participants' experiences through a lens focussed with reference to biomedical traditions and culture. As recounted by Stella, Joan and Toby, a preliminary diagnostic label bestowed through expert assessment relieved some of the anxiety and social wounds associated with having no label at all. However, in the longer term, these labels (*'idiopathic'*, *'chronic'* and *'genetic'*) and the associated terminology (*'peripheral neuropathy'*) were formulated in an exclusive language that hid an underlying uncertainty about what was wrong and assumed a specialist knowledge which, without expert interpretation, held little meaning for the majority of participants. Most participants also made an explicit reference to the genetic issues associated with the progressive ataxias. It was clear that this topic was psychologically troubling and at the time of the interview the existential concerns seemed to be of particular relevance for Stella, Graham and Hugh.

The findings from this work support yet deepen those of Daker-White et al. (2011) who investigated the experiences of the diagnostic process for people living with a progressive ataxia. As discussed and critiqued in chapter 3 (Literature Review), this was a large international study which examined English language internet discussion forums specifically for people living with ataxia. The main themes from this data clearly resonated with the topics discussed by participants in the present study. The authors identified diagnosis as an arduous and lengthy process which commonly resulted in test weariness, increased frustration and the questioning of medical expertise, particularly when previous diagnoses were changed or withdrawn. Contributors stressed the importance of having a medical label but maintained that a diagnosis of idiopathic ataxia was a non-diagnosis because it failed to satisfy the need for concrete explanations. Symptoms were also commonly misunderstood and credibility was found to be a particular issue for people living with episodic ataxia (like Joan).

One of the other main themes to emerge from Daker-White et al. (2011:125,126) was the concept of 'diagnosis as privilege'. The basic premise underpinning this theme seemed to suggest that whilst all people living with a progressive ataxia had to contend with an incurable condition, those who had the 'privilege' of a firm diagnosis might be 'better off' than those who had either no diagnosis or the non-diagnosis of idiopathic ataxia. The present study has added a more contextualised understanding to this argument, in that, with respect to Hugh and Harry's accounts, a definitive diagnosis may bring with it new uncertainties or terrifying consequences. These consequences impress

themselves on the person not just in the moment of diagnosis but project to a troubling future, and, for some, raise questions about the past with respect to unknown family histories. More accurately, rather than being better off, a definitive diagnosis might be better understood as having complex and highly situated ramifications that may invoke another set of problems that have to be managed, incorporated and understood within the contexts of the lifeworld.

Daker-White et al. (2011:120) also suggested that people who were unable to secure a diagnosis changed their priorities from 'getting a diagnosis' to 'learning to live with it'. Conversely, the accounts of the participants in the present study suggested that learning to live with an idiopathic progressive ataxia was not something they did or prioritised when they had exhausted or had been exhausted by the diagnostic process; rather it was something they did alongside and in the midst of these troubling and confusing times. This important topic is considered in-depth in the following chapter.

The experiences recounted by participants in this study also resonated with the findings of White et al. (2010) who interviewed 42 adults living with Friedreich's ataxia (FRA) to explore their perceptions of transitional life events. Similar to the findings of the present study, the emergence of symptoms was identified as a particularly significant period where participants encountered self-doubt and isolation when medical practitioners were initially unable to identify causation. Some participants also spoke about their concerns about passing on the FRA gene although this did not seem to be a particular focus of their accounts, perhaps for similar reasons as suggested for the present study. White et al. (2010) also reported that participants experienced both positive and negative interactions with healthcare providers. Negative experiences were derived from perceptions that clinicians had limited knowledge of Friedreich's ataxia. Positive encounters were characterised by a willingness to listen and by demonstrating a compassionate and genuine interest in the fullness of the participants' lives.

The second super-ordinate theme focussed on the complex dilemmas participants faced about the inheritable potential of progressive cerebellar ataxia. In the main, they did not dwell on these issues. However, three participants spoke at some length and hinted at complex psychological concerns that were not only deeply personal (*'I don't know which pigeon hole to put myself in'*, Graham) but also embedded in highly situated family contexts (*'the children don't know that they could have it, we've kept it quiet'*, Hugh). These accounts support Williamson's (1999) view that inheritable conditions raise psychological issues that have a qualitatively different feel to those of non-inheritable disorders. This is because concerns about inheritance not only challenge or threaten an

individual's sense of identity in a fundamental way but also implicate members of the same family. Hugh's account showed that late on-set conditions seemed to raise particular issues especially when the variant gene may have already been passed on. Feeling responsible for the life of future generations and the likely difficulties faced by children, formed part of the psychological landscape of living with cerebellar ataxia. Feelings of guilt in this situation can be intense (Kay and Kingston, 2002).

The present study also revealed that cerebellar ataxia raised particular issues that add a new perspective to the literature concerned with understanding inheritable neurological conditions. A sense of chronic uncertainty emerged from participants' accounts, not only in terms of living with a condition that was difficult to diagnose and for which there is no known cure but also the uncertainty that accompanied not knowing whether or not the condition was hereditary and whether it could be or already had been passed on. These experiences differ from the still deeply troubling but starker realities and certainty faced by people living with a condition such as Huntington's disease. In this condition genetic testing provides a definitive result, and a positive test affords unequivocal information about risk of inheritance thus informing reproductive decision-making (Smith et al. 2002).

It is perhaps significant that all but one participant directly raised or hinted towards the psychologically troubling implications of living with a potentially inheritable condition and the difficulties faced in trying to make sense of family history and handling ambiguous information about future generations. These new findings may have implications not only for GPs and neurologists but also for geneticists and health psychologists. However, it might be important to look more closely at the ways in which people experience living with these possibilities and risks, especially the chronic uncertainty that might be particular to this condition. IPA seems well placed to explore these deeply personal topics and to capture the richness and complexity of family experiences (Chapman and Smith, 2002).

Attending more closely to the themes identified in this chapter, this next section explores the intrinsic authority of biomedical discourse and the juxtaposition of two cultures: the meaning-centric instincts of the participants and the apparent disease-centric focus of medical specialists.

There is a long history of research into doctor-patient interactions that has consistently identified problems associated with oppressive and disempowering communication styles (Gwyn, 2002). This type of discourse depends upon medical reductionism and

jargonistic terminology and it is perhaps surprising that it persists long after the benefits of partnership-working have been established (Coulter, 1999; Epstein and Street, 2011). Rather than being a 'relic of the bad old days' (Gwyn, 2002:167) this type of communication still seemed to be, at least for some participants in this study, a contemporary feature of clinical practice. People with 'sticky clinical problems' such as on-going symptoms with repeatedly negative test results and chronic incurable conditions seem particularly vulnerable to these uncomfortable interactions (Richards, 1990:1407). Unfortunately the progressive cerebellar ataxias fit this mould. This condition is complex, causation is often elusive, and it is uncommon in general practice. Furthermore, there are as yet no reliable disease modifying interventions, and there are no clinically valid treatments that bring symptomatic relief to the primary impairments (Finsterer, 2009, Klockgether, 2011).

The sense of abandonment (through being discharged or disbelieved) and frustration (through on-going diagnostic uncertainty and being denied access to valued sources of knowledge) recounted by the participants in this study was in some ways similar to those expressed by people living with MS (Johnson, 2003) and chronic fatigue syndrome (Dickson et al. 2007). However, the progressive ataxias are not contested or medically unexplained in the same way that a condition like chronic fatigue syndrome is. Also, some of the uncertainty and anxiety of living with MS described by Johnson (2003) may have been relieved more recently, albeit only modestly. For example, progress has been made in the biomedical management of MS with the advent of improved diagnostics and advances in immunology, alongside this has come a deepening appreciation of its psychosocial context, and the development of information sources that support collaboration and empowerment (Simmons, 2010). The position for people living with the progressive ataxias would seem very different in this regard. Firstly, diagnosis for many people remains an uncertain and persistent concern, whilst a firm diagnosis raises further issues about inheritance and the value of genetic testing (where available). The threat posed by a serious genetic condition carries a heavy emotional burden (Rolim et al. 2006) and the associated anxiety and uncertainty is thought to cause a kind of chronic stress (Bird, 1999). Secondly, although research is on-going, as noted above, there is currently no cure and no intervention that can relieve the symptoms or alter the trajectory of progression for the majority of the progressive ataxias.

What emerged from this study was the participants' desire to be heard, to be respected, informed and understood within the particular contexts of their social worlds, not just by

general practitioners but also by medical specialists, such as neurologists. These needs are the moral foundations that underpin the concepts of patient-centred care (Epstein and Street, 2011). Unfortunately, incurable conditions such as the progressive ataxias are thought to place the 'highest demands on doctors' skills' in this regard (Williams, 1990:67). Resisting historical traditions (such as the biomedical tradition) requires special effort, it involves 'rising to a higher universality that overcomes not only [one's] own particularity but also that of the other' (Gadamer, 2004 [1975]:304). For healthcare practitioners this means understanding what is at stake in consultations with patients living with a condition like progressive cerebellar ataxia. With respect to the present study this might mean acknowledging the patient's powerlessness and vulnerability. Communicating with patients in this situation therefore demands more than giving information. It requires interpretation of information in a way that makes sense and does not add to the burden of living with chronic illness. In other words, it means moving towards a model described by Salmon and Young (2005:231) in which 'communication is tailored to the illness, the patient *and the moment*' (emphasis added).

Healthcare practitioners (and perhaps other organisations) may need further support to transcend the traditions of their cultures in order to attend to the particular needs, anxieties and concerns of people living with rare, complex, progressive and incurable conditions. Fortunately, efforts to promote a better understanding of the progressive ataxias has been one of the priorities of Ataxia UK and recent publications for general practitioners, medical specialists and rehabilitation practitioners may go some way to filling some of the gaps (Ataxia UK, 2009 (with a contribution from this researcher); 2010). Furthermore, research that prioritises the perspectives and experiences of people who live with a progressive ataxia such as the present study and the work of Box et al. (2005), Brook-White et al. (2010) and White et al. (2011) adds to Boutté's (1987, 1990) pioneering research in this field, and through incremental accretion may establish a corpus of work capable of informing and changing practice.

## **8.5 Conclusion**

This chapter presented participants' perceptions of their experiences of the clinic, and the biomedical contexts in which life with ataxia may be understood. The findings lend support and expand previous work (White et al. 2010; Daker-White et al. 2011) and by doing so deepen the understanding of issues that may be significant and troubling for others living under similar circumstances.

## Chapter 9

### Super-ordinate Theme 4

***'Whenever it gives you a problem find a way round it, or fix it, you know' (Harry)***

**Description: Wrestling control in the face of uncertain and changing forces**

#### 9.1 Introduction

This chapter explores the ways in which participants talked about taking steps to understand and reinterpret their condition on their own terms. It describes their attempts to take control of ataxia and its impact on their sense of identity within the rich contexts of their everyday lives.

Disruptions and challenges seemed to form part of the fabric of participants' worlds and were intertwined with and managed alongside the more hopeful and positive aspects of their lives. Three subthemes examine this complex interweaving and the ways in which participants coped with the turmoil and upheavals of living with ataxia. The first subtheme attends to participants' accounts about seeking out sources of information and support and the meaning these held. The second subtheme looks at the ways in which participants described a particular stance or philosophy towards living with ataxia. The different approaches seemed to help maintain a positive focus on what could be achieved or fought for, and helped some participants retain a sense of purpose through connecting with and helping others. The third subtheme explores the particular ways in which participants managed to preserve valued roles and interests, as well as sustain important relationships whilst also encountering and dealing with frustrations, sadness and setbacks.

Quotations from the majority of participants (n = 11) have been used to convey this super-ordinate theme. Extensive extracts from some participants have been used because these expressed the theme most clearly. Shorter extracts have been used to support the main quotations and to demonstrate the extent of the shared theme. Divergent experiences have been indicated in the text.

#### 9.2 Subtheme 1

***'You're not on your own' (Scott)***

**Topic: Seeking out information and drawing support from informed others**

As noted in the previous chapter, most participants described looking to medical practitioners for expert advice and partnership, as trusted people with whom they could

share their concerns and discuss ways of managing their condition. However, most narratives (n = 10) communicated a deep sense of abandonment and frustration with what was perceived as a lack of knowledge and understanding from healthcare professionals. Seemingly exasperated and no further forward, participants described feeling obliged to find their own ways of coping with this difficult situation. This subtheme focuses on the participants' search for alternative sources of information and support from others with ataxia and is summarised in Table 9.1.

**Table 9.1 Seeking Support and Information (n = 7)**

Participant	Extract	Page: line number
<b>Seeking Alternative Information</b>		
Susan	<i>'I take literature from Ataxia UK to the consultants that I see and show them you know what I should expect in the way of a diagnosis'</i>	5:19
Stella	<i>'[...] reading various information [in the Ataxian]'</i>	1:26
Hugh	<i>'[Ataxia UK] they should tell you what's available'</i>	6:20
Hugh	<i>'Go on the foreign [internet] sites that's where you get the information'</i>	6:28
Bill	<i>'There's so much on the internet which is snake oil stuff'</i>	4:19
Graham	<i>'[the Internet] they're not credible to me'</i>	17:4
<b>Drawing Strength from Others with Ataxia</b>		
Graham	<i>'If we all club together we've got more of a voice than we have individually [...] that's why I support the support groups'</i>	18:4
Scott	<i>'[...] it's just nice to know that there's somebody else out there'</i>	18:16
Bill	<i>'[BBC podcast] you can get some kind of comfort from it'</i>	13:44
Susan	<i>'They're grateful to me for running the group'</i>	8:15
Jim	<i>'If I can help others, or help others help others, then that's part of the reason I exist'</i>	1:29

Perhaps in response to what seemed to be for most participants an immensely frustrating experience in the world of biomedicine, the majority (n = 11) talked about searching for additional information and alternative sources of support. Stella and Susan, for example, used The Ataxian (the members' magazine produced by Ataxia UK) to underpin their requests for further diagnostic tests:

*Susan: 'I take literature from Ataxia UK to the consultants that I see and show them, you know, what I should expect in the way of a diagnosis.'*

*Stella: 'After [...] reading various information [in the Ataxian] which stated that you should never be discharged because of new things coming up, I went back to my GP and got him to [re-] refer me.'*

The above quotations seemed to reinforce the impression identified in other accounts (chapter 8) that GPs and consultants were perceived as lacking expertise and up-to-date information. Furthermore, there is a suggestion in these quotations that Susan and Stella may have found it difficult to be heard in these consultations. The Ataxian therefore offered them both a voice and a borrowed authority compatible with the type of knowledge recognised by their medical practitioners. Re-balancing the power in this encounter by bolstering their status, created an opportunity for Stella and Susan to gain some control over medical referrals and consultations.

Ataxia UK was not regarded positively by all participants. Hugh, for example, expressed reservations about the value of Ataxia UK which seemed to reflect his overall distrust of the medical profession and his belief perhaps that there was some sort of medical conspiracy to keep people with ataxia ignorant and powerless:

*Hugh: 'They [doctors] just don't tell you what's available. Even the Ataxian Society [Ataxia UK] they should tell you what's available so you can say 'Let's try this'. [...] But they don't. They should but they don't. The trouble is with the Ataxia Society, they've got quite a few doctors on their Board, so that's probably why they don't do it.'*

Hugh assumed that Ataxia UK was run by medics; in fact its Board of Trustees is composed of several professional groups as well as people with ataxia or those caring for others living with ataxia.

Harry rejected Ataxia UK for not being helpful enough (*'the horror that I came into this Society [Ataxia UK] and it's like nobody was [...] there's no serious help, help to help yourself'*). Toby found the thought of meeting others via Ataxia UK, particularly those more disabled than himself, too negative. He avoided meeting those who might reveal a possible unwanted future self (*'you don't want to see people in maybe in a far more advanced stage of the condition, yeah? Cos it might depress you'*).

In the search for reliable and meaningful information, the Internet also divided opinion, Graham appeared wary of internet sites; *'they're not credible to me'*, as did Bill; *'There's so much on the internet which is snake oil stuff that by and large that's worth ignoring'*. Hugh, perhaps because of his distrust of traditional, especially medical, sources of

information seemed less suspicious of the internet; *'Go on the foreign sites that's where you get the information from'*.

Information gathering, and learning about ataxia, formed an important strand of managing life with ataxia for these participants, at least in part because it might be understood that information afforded agency and perhaps a sense of competence in a situation where "expert" knowledge and understanding was lacking. However, at the same time, some participants seemed to be seeking out others with ataxia for some sort of fellow feeling, mutuality and support which perhaps worked to resist feelings of isolation and abandonment. The following exchange between Graham and Scott provided a good example:

*Graham: 'It's beneficial to meet people like Scott that have got similar ... not exactly the same symptoms as me but at least we're on the same page.'*

*Scott: 'You're not on your own'*

*Graham: 'Yeah'*

*Scott: 'You can relate to somebody else who's got what you've got and you can have some kind of benchmark of where you are.'*

*Graham: 'That's right, yeah.'*

*Scott: 'I suppose ... it's just nice to know that there's somebody else out there who's suffering just as much as you are I suppose. I don't mean that nastily, it's just ...'*

*Graham: 'Yeah, that's right'*

The opportunity to appeal to another's experience, to know that they are *'on the same page'*, also appeared to provide both Scott and Graham with reassurance and an important sense of connection that despite everything they were not alone; *'there's somebody else out there who's suffering just as much'*. The reference to *'benchmark'* in the above extract seemed significant in this context, perhaps others in a similar situation offered a fixed point of reference when everything else seemed in flux and unknowable. Bill seemed to find a similar sort of consolation from listening to a regular online broadcast about people living with disability:

Bill: *'Like a real club, it has its own language and kind of knowing glances, whatever, that you belong to it and you can get some kind of comfort from it. [...] In terms of you're not the only one.'*

For Bill, learning about others in a similar situation perhaps reduced his sense of isolation (*'you're not the only one'*) and being part of a larger group appeared to reduce some of his illness related suffering (*'you can get some kind of comfort from it'*). Similarly for Jim, he said of his local support group: *'It's good for me because it shows I'm not alone'*, and Joan *'talking with other people, I would hear what symptoms they had'*. These sorts of connections with knowledgeable others could be understood as forming a kind of collective strength that worked to offset the feelings of vulnerability, powerlessness and stigma identified by participants in previous chapters.

### **9.2.1 Summary**

Participants' lives were populated with friends, family and work colleagues, nonetheless, it seemed they retained strong feelings of isolation, as if living with ataxia set them apart from others and disrupted their sense of belonging in the world. They also struggled to make sense of what seemed in their experience an unknowable and uncertain condition. Disappointed by medical specialists, participants described looking for support and information from other sources. Their search was not confined to objective facts about ataxia, it was also relational. They described seeking out similar others, those who could offer not simply useful information but also a sense of inclusion, belonging and reassurance that was absent from their encounters with those in the biomedical world. Reaching out to others who shared the participants' experiences might have offset feelings of isolation and helplessness whilst, at the same time, inspiring confidence in their ability to persevere and deal with the difficulties they encountered.

### **9.3 Subtheme 2**

#### ***'Focus on what you can do, not what you can't do' (Toby)***

##### **Topic: Taking a Stand: personal philosophies for living with ataxia**

The majority of participants (n = 9) talked about adopting a particular philosophy or an approach to living with ataxia that seemed to enable them to live their lives in a way that fostered self-determination and which went some way towards resisting the uncertainties and disruptions that accompanied life with ataxia. Two approaches to living with ataxia were identified (Table 9.2) and are discussed below.

**Table 9.2 Approaches to Living with Ataxia (n = 7)**

Participant	Extract	Page: line number
<b>Focus on the Positive</b>		
Toby	<i>'Know your limitations [...] try to have a positive outlook and focus on what you can do, not what you can't do'</i>	26:19
Susan	<i>'I don't concentrate, to be honest, on the things I can't do'</i>	7:8
<b>The "Fighting Spirit"</b>		
Harry	<i>'Beat it, [...] find a way round it, fix it'</i>	3:7
Julia	<i>'If I wanted to stay independent I had to fight as long as I could. [...] I'm fortunate enough and bloody minded enough to hang on as long as I can'</i>	15:20
Stella	<i>'My biggest thing now is to try and stop the rot really ... [...] I think that's the only way. That's all I can do anyway'</i>	25:28
Scott	<i>'You've got to have a structured plan of attack'</i>	16:11
Joan	<i>'I'm learning to manage it better, because in the end you have to manage it'</i>	3:29

Toby and Susan talked about prioritising what they were able to do and about putting activities that were no longer possible behind them: *'focus on what you can do, not what you can't do'* (Toby). This approach seemed to foster a strong positive outlook. Both Susan and Toby recounted experiences where they had encountered loss of or threats to valued roles as part of the consequences of living with ataxia. However, instead of dwelling on these painful episodes, and whilst not concealing the hurt involved, they described focusing on a more positive aspect of their lives. For example, Susan described looking after her grandchildren as a *'big part'* of her life but she seemed worried that it was a role at risk:

*'My daughter-in-law doesn't leave [the grandchildren] with me very often. And I wonder if she thinks I can cope, although I have managed to come down the stairs with a baby on my lap, on my bottom!' [Smiles]*

As discussed in chapter 7 (Identity, Stigma and Disrupted Embodiment in Public Spaces and Places), Susan seemed to suspect that her daughter-in-law was wary about leaving her with the grandchildren. However, within the same sentence, almost without drawing breath, she offset this troubling issue through focussing positively, declaring her achievement and celebrating her ingenuity. Susan's positive approach (*'I don't concentrate, to be honest, on the things I can't do'*) acknowledged but at the same time

countered and overcame (at least temporarily) the threat to a valued role. This philosophy perhaps offered Susan a sense of control, a way of showing, at least to herself but also to others, that she was, for the time being, capable of coping. Small victories and accomplishments like these, even within a bleaker context, seemed to help sustain Susan to maintain a positive outlook and to resist the harmful impact on identity discussed in chapter 7.

It may be important to acknowledge that neither Susan's or Toby's life had been untouched by serious illness prior to developing the symptoms of progressive ataxia. Their experiences of these earlier difficulties may have had some bearing on their way of living with ataxia, particularly with reference to maintaining a positive outlook in coping with adversity. For example, Susan's approach seemed to be strongly influenced by witnessing her mother struggle with a painful, long term condition:

*Susan: 'her pain was excruciating and I know that what I suffer is nothing like [that]. And when I wake up all rigid, and then I get going, to me that is such a relief, I always think of my mum, what it must have been like. So um ... then I don't think about my pain any more, you just get through the day.'*

In the above quotation, Susan compared her mother's severe and unrelenting pain with her own. Crucially Susan described gaining some respite from her pain whereas it seemed for Susan that her mother never did. Perhaps by respecting what Susan may have understood as her mother's courage and resilience, and whilst not underplaying the severity of her own pain, she used her mother's example to develop a cognitive strategy that helped to endure her own pain and to persevere. As with her general philosophy, Susan seemed less inclined to dwell on the negative aspects of her condition and instead refocused on what she could achieve, even if, at times this meant simply surviving from day to day: *'you just get through the day'*.

Toby had survived a life threatening condition a few years prior to the development of ataxia symptoms. He believed that coming through the hardships associated with this crisis had conferred a buffer of resilience on him that may have helped withstand some of the more destructive or challenging aspects of living with ataxia:

*Toby: 'for myself I think having had the tumour that made me a really strong person because I had to deal with that.'*

Toby and Susan used a cognitive strategy to help manage their lives with ataxia which focussed specifically on what was possible and what could be accomplished. They

described drawing strength from previous illness experiences which appeared to help sustain a positive outlook even in adversity. Within a similarly positive framework Harry, Julia, Stella, Scott and Joan articulated a more adversarial approach in line with the “fighting spirit” which helped to preserve their independence as well as their participation in meaningful activities and interests (Table 9.2). Harry’s account provided a valuable insight into this aspect of living with ataxia. Harry’s philosophy was to find ways to outsmart the effects of ataxia whilst cautiously acknowledging that it had, and would continue to have, long term consequences:

*Harry: ‘I don’t consider it to be a threatening condition. It’s not fatal, you ain’t gonna die from it, so you’ve just got to beat it. Well ... try and beat it, you know. Whenever it gives you a problem find a way round it, or fix it, you know.’*

Drawing on adversarial metaphors, Harry objectified the ataxia (*‘beat it, find a way round it, fix it’*), externalising it in this way may have given him some sense of control, a way of living with ataxia that despite anticipated setbacks, preserved, as best he could, his way of being in the world. For example, Harry seemed to admit the hurt associated with his inability to do some activities: *‘Can’t do it no more. And then that sort of thing, it’s like, bites a bit’*. The reference to *‘bite’* here says something quite powerful about Harry’s sense of loss, as if relinquishing valued activities actually takes something out of him or wounds him. However, he explained that at the same time; *‘You evolve, you evolve to suit where you’re at. [...] It’s thinking my way around these things. I mean it’d be so easy to just go ‘No’ and forget about it.’* For Harry, this philosophy, his way of living with ataxia, fighting and working hard to shape his life in a way that he valued, also seemed to act as a means of preserving a preferred identity. He spoke about alternative identities that he strongly resisted. In the following quotation Harry described what he might have considered the antithesis to his own approach to living with ataxia:

*Harry: ‘... you know people are just ‘I’ll have an electric wheelchair and I’ll have a dog for the disabled’, and just give in, you know. It’s just ... you know it’s not a fight thing, [...] they think they’ve got ataxia, that’s it, you know, just give up, curl up in a ball until you die sort of thing.’*

Harry described an acceptance of passivity that he had identified in others’ behaviour that he found almost unthinkable. For Harry, inactivity was suggestive of lack of fight, an easy way out of the hard work of living purposefully with ataxia, as he said later in his account: *‘it’s so easy to sit at home, watch telly and wondering about the next episode of ‘EastEnders’*. It seemed that Harry would rather persevere with his way of living with

ataxia which perhaps sustained a positive sense of self, than give into the submissive behaviour he thought he saw in others:

*Harry: 'More and more things don't work, you know. You can't just do a couple of pull ups in the morning and then think 'Oh that's it for a week'. You have to do it like again and again and again'.*

Harry had developed a philosophy, a way of living with and adapting to recurring difficulties that still allowed him to pursue meaningful goals, the kinds of things he was interested in. At the same time he acknowledged that this approach was not straight forward, it was demanding: *'You have to do it like again and again and again'*. The repetition in this sentence seemed important because it emphasised that managing life with ataxia was not "simply" a cognitive strategy, it had to be translated into persistent behaviour which might, under any circumstances, be difficult to sustain. Furthermore, Harry seemed to admit to himself that the future may unfold in ways that could threaten his preferred way of being in the world and his hard earned sense of self. For example, with reference to the importance of regular exercise Harry explained: *'otherwise electric wheelchairs here we come, you know'*. Here, it is almost possible to conjure up an image of Harry sliding down a hill into a wheelchair, digging his heels in all the way down. It powerfully captures his resistance to this possibility and how hard he is fighting to stay in control and to preserve his sense of self.

Participants' accounts suggested that ways of living with ataxia were not easily developed or implemented and often involved a trial and error approach; some strategies were found to work, whilst others were temporarily or permanently abandoned or adjusted as life was further disrupted and as new challenges were confronted. The following quotation from Hugh's account illustrated how, at times, he experienced life as almost engulfed by the effects of ataxia. Hugh had lived with ataxia for many years but seemed to be in the middle of a period of transition or crisis:

*Hugh: 'it takes me longer and longer to recover, so if I do too much it takes me longer to recover [...] I've got some weights so I do a bit of that but even that I seem to ... don't know what it is, motivation gone, it seems too much, like ... getting in from work, I'm so tired, I just want to sit down. Some days I'm good, some days I'm bad. It's hard, it's really hard.'*

In the above quotation Hugh seemed almost consumed by the fatiguing effects of ataxia. Even though some days may have been better than others, at its worst the effects

seemed to penetrate his whole being: *'Some days I'm good, some days I'm bad'*, emphasis added. Hugh described everyday life as gruelling and exhausting and often beyond the implementation of his usual coping strategies; *'motivation gone, it seems too much'*. Overall, the physical and psychological effort of getting through his day seemed almost too much to bear; *'It's hard, it's really hard'*. Several of the participants seemed to describe sharing at least some aspect of Hugh's experience:

*Scott: 'it's not much of a life at all when the symptoms come on strong [...] you don't have a social life as such [...] I do try to get out as much as I can to stave off the symptoms of depression, but it's very difficult – you go out then you do a very short journey, you'll be back inside.'*

*Graham: Some days it is quite difficult to get up and go out. So that's fine if you've got a plan, say a work plan to go to work, but then when you come to something else that's not quite as important as going to work, it can be quite difficult. [...] So sometimes I do give in [...] so I don't go out.'*

These quotations from Graham, Scott, Hugh and Harry seemed to convey the struggle and effort involved in keeping going and in implementing positive strategies and ways of coping with ataxia. Sacrifice and compromise seemed to be a necessary part of living with this progressive condition. Often due to fatigue but also as a result of accumulative physical deterioration, adjustments had to be made; some activities were abandoned at least in the short term but also some were lost for good and new problems had to be attended to and managed.

In addition to assertions that they maintained a positive outlook and adopted an adversarial approach to coping with ataxia, membership or leadership of a support group also seemed to confer an affirmation of the sense of self that in turn appeared to help these participants manage life with ataxia in a positive way. Graham, for example, drew strength from being part of a larger and more powerful group because he explained that in a situation where he felt he had no voice, the larger group offered perhaps a greater sense of authority and the right to be heard:

*Graham: 'If we all club together we've got more of a voice than we have individually [...] that's why I support the support groups.'*

Jim and Susan seemed to gain a sense of purpose and possibly esteem from supporting other people living with ataxia. Jim for example seemed to derive satisfaction from being able to offer advice: *'I got an e-mail back, it's really helped, which is good.'* Similarly

Susan seemed to find organising a support group personally rewarding: *'they're grateful to me for running the group'*.

Two participants recounted quite different experiences. Ted, being relatively newly diagnosed still seemed to be making sense and grappling with the effects of ataxia on a day to day basis and did not describe any particular strategy or way of coping with ataxia that he had found helpful. Bill however seemed to be in rather a different place:

*Bill: 'You get used to it, get to the end of the week, you feel 'that's one more down'. So we survive, we've got by. You know we're still around, we're still here. So I think 'Oh, it's a relief' [...] I'm not sure how it works, I can't explain the mechanism, but it just happens, you think, 'Morning, Friday again, good'.*

Unlike most of the other participants Bill seemed primarily to endure life with ataxia. Although Bill still participated in some activities that gave him comfort, taken as a whole, the context of his everyday life was marked by a kind of patient fortitude that differed in both tenor and perspective from the other participants' stance towards their lives with ataxia. With echoes of Susan's account, the above quotation seemed to suggest that Bill framed his life in terms of survival, an existence measured in individual weeks suffered through but successfully negotiated. Bill spoke both of himself and his wife. Getting through the week was a joint effort: *'we survive, we've got by', 'we're still around, we're still here'*. Bill seemed to suggest that the struggle was not his alone, his wife, as his main carer, also had to endure, and the regular Friday appraisal observed their combined achievement in getting through another week. This difference in attitude compared to other participants in the study may also have reflected a latent anxiety about his wife's quality of life. By facing these difficulties together they also suffered them together. Bill the individual was *'still here'* and it was perhaps a relief to be alive. However, at the end of another painful and effortful week not only was Bill *'still around'* but so was his wife: *'we're still here'*. Bill and his wife as a couple were still together, she was still with him. The repetition of *'we'* and *'still'* seemed to emphasise the fact that, in a positive way, nothing had changed, at the most fundamental level perhaps, she had not left him.

### **9.3.1 Summary**

Most participants described a personal philosophy which acknowledged that ataxia was a feature of everyday life without entirely surrendering enjoyable and meaningful activities to it or underplaying its negative effects. Taking a positive stance might have

bolstered the participants' sense of autonomy and helped them cope with some of the more disheartening consequences of living with this progressive but uncertain condition. However, maintaining a positive focus and deriving a sense of satisfaction and achievement required sustained effort and reappraisal in light of permanent or temporary setbacks and physical decline. Participants' willingness to talk about their struggles as well as their successes worked to offset any scepticism that the "fighting spirit" philosophy could be seen as a self-presentational strategy adopted for the purposes of the interview or, as suggested by Radley (1993), a reflection of a cultural imperative to stoically accept impairment and to heroically battle against the effects of illness. For some participants, the effects of ataxia seemed overwhelming and, at these times, strategies or ways of life that usually conferred some benefit were permanently or temporarily abandoned or rendered ineffective. Recurring motifs about ways of managing and living with these disruptions could be traced through the participants' accounts; these are discussed in more depth in the next subtheme.

#### **9.4 Subtheme 3**

***'When I do something, I do it in bite size' (Scott)***

**Topic: Finding a way to preserve valued roles and interests**

All participants recounted experiences where their natural way of being had changed and was changing as a result of living with ataxia. Difficulties and setbacks were described as part of the pattern of everyday life and were woven in amongst the achievements and the satisfaction associated with accomplishing, in some acceptable way, valued activities and sustaining important relationships. Managing therefore encompassed a kind of dynamic working out. Living with a progressive and unpredictable condition meant that strategies had to evolve. Plans and activities were re-evaluated in light of on-going and unpredictable disruption. Therefore managing to forge a meaningful life with ataxia could not be understood without referring to the ways in which it was always in progress and also shaped by temporal considerations. Finding acceptable ways to pace activities, for example, offered the opportunity to maintain involvement in enjoyable and rewarding occupations. The following extract from Joan's account provides a useful introduction to this subtheme:

*Joan: 'I'm daft if I allow myself to do more than half an hour in the garden, because by three quarters of an hour I'm struggling. But half an hour it's such a short time and very trying. Although the place looks tidy, I'm not a very tidy person. Do you know what I mean? So I'm trying to be a bit tidier as I go along because otherwise it's too much to*

*deal with. I thought when I came here I wouldn't need anyone with the housework, but I do. And with the ironing ... and the garden [...] I don't go out in the evening anymore which is trying. I can't so that's changed.'*

The repeated use of the word 'trying' in this extract seemed to communicate not only a sense of endeavour and perseverance but also irritation. Joan seemed to feel that she had to almost become a different person just to cope with ataxia. In addition to reluctantly abandoning parts of her social life and seeking help with household activities, Joan also talked about the frustration she felt in having to apportion a specified time to her activities; measuring out how much time she could spend doing something before she had to stop. As demonstrated in other work (Reynolds and Prior, 2003) pacing seemed to confer mixed benefits. Pacing allows participation in meaningful and enjoyable activities but at the same time it may be perceived as giving the illness the upper hand, a forced choice rather than a positive lifestyle decision. However, Joan had managed to preserve some of her interests and seemed to derive at least some satisfaction from doing them in a modified way:

*Joan: 'When I go to [my son's] house I can actually achieve so much because I mean I actually can help him do some painting ... because he'll get out all the paraphernalia, puts the chair there, opens the paint tin, puts the brush in my hand and I can paint. And of course that makes me feel very good. Then he will gear it to three quarters of an hour and make me stop, even if I want to go on, which I generally do. And the same with gardening in his garden which I love doing. I can do that as well, and it feels so much more positive and good, because I've achieved something rather than not a lot.'*

In a very practical way, it seemed important that Joan's son set up the activity and imposed a completion time so that Joan could expend her energies on the most pleasurable and rewarding part of gardening or painting. The above quotation possibly suggests that Joan's son seemed to understand his mother's difficulties and constraints, and more importantly perhaps he accepted them and helped her to manage them in a positive way. Joan seemed to derive a firm sense of satisfaction and enjoyment from not only doing the activities she described but also perhaps by spending time with her son. This sense of satisfaction may have been enhanced because Joan had been able to do something for her son in return; decorating his house and doing his garden. At a deeper level of interpretation, what seemed important here for Joan was not simply that she could do an activity that she enjoyed but, as a mother helping out her son, the richer reciprocal social contexts underlying this activity perhaps provided deeper meaning and a stronger sense of well-being and contentment.

Graham and Scott shared Joan's frustrations about fatigue and apportioning time to activities, they both spoke about trying to complete tasks whilst preserving scarce energy resources:

*Graham: 'Instead of doing a day gardening or decorating or whatever, you can do an hour. And sometimes it takes longer to actually get set up, do something for half an hour, three quarters of an hour and then put everything away again ...'*

*Scott: 'I support that because when I do something I do it in bite size as I call it. I do it in a little section where I can spend a fairly reasonable comfortable short period of time, which gives me a bit of time to clean everything up and another day I do it again. So what would have taken me about two hours when I was healthy takes me several weeks now.'*

The sense of measured time and living with a heightened awareness of time articulated by Joan, Scott and Graham was echoed in other accounts. Participants spoke of a loss of spontaneity, and of activities abandoned or curtailed, perhaps best summed up by Susan;

*Susan: 'It's slowed me down and that can be quite frustrating to have your life slowed down. Because apart from anything else it shortens the time that you have. All the things that you used to be able to do in an hour or a day, everything takes so much longer, so you don't have so much time.'*

For Susan, the effects of ataxia seemed to have compressed or rationed time; *'it shortens the time that you have'*. Time was also slowed down because, in similar ways to Joan, Scott and Graham, everyday tasks could take up a disproportionate amount of time, leaving little possibility of doing anything else. In this sense Susan felt that her whole life had *'slowed down'*.

In this next extract Bill described his experiences of family mealtimes:

*Bill: 'I mean the big frustration is not being able to eat and speak at the same time, because I'm used to kind of having long conversations during meals and you know you would like to say things and join in, argue, whatever. When you've got to sit quietly it's quite difficult at times. Because you think of exactly the right thing you'd like to say and after the meal you say 'You know when you said such and such, well how about ...' then it didn't work, the moment was lost.'*

In the above quotation (as discussed in chapter 6, The Embodied Experience of Living with Progressive Cerebellar Ataxia) Bill started with a straightforward description of the physical challenges of ataxia, the difficulty of combining eating with talking, however, the main body of the extract quickly moved towards explaining the meaning of this experience. A descriptive analysis of the text suggested that two physical impairments (difficulty eating and difficulty speaking) combined to rob Bill of a valued occupation, active involvement in dinner table discussions; *'I'm used to kind of having long conversations during meals and you know you would like to say things and join in, argue'*. A deeper reading might propose that sitting quietly was not Bill's natural way of being in the world; it was a way of being imposed by ataxia, *'you've got to sit quietly'* (emphasis added). The final sentence; *'After the meal you say 'You know when you said such and such, well how about ...' then it didn't work, the moment was lost'*, speaks for Bill's attempts to recapture a specific opportunity but also seemed to connect with past attempts. Listening to him it felt as if he had tried this way of picking up lost conversations or lost moments many times.

What seemed to be glimpsed in the above extract was the reiteration of the physical assault of ataxia on the body but also, the sense of diminished possibilities. Sitting still, all his effort concentrated on eating, chewing and swallowing, Bill was physically present, at the table with the others, but the interesting conversations that he would have liked to be part of were going on around him. When he tried to catch up he found himself temporally out of step, ready to discuss a moment in time that the others had long ago left behind. In this sense his social presence had been lost.

Bill had worked out a way to counter some of these negative effects; he discussed *'politics and stuff'* with two volunteers, each of whom visited Bill once a week. Another volunteer accompanied his wife on trips which, via the photographs she took, she then shared and discussed with Bill. However, it would seem to be too simplistic in terms of interpretation to overstate the way in which these strategies may have compensated for what Bill and by extension his wife had lost. The volunteers provided a substitute for dinner table discussion but, without reading too much into Bill's account, it would seem perhaps that the loss of these highly valued family debates and conversations inevitably and irreversibly diminished some the richness and depth of Bill's life experience. Importantly for Bill, he seemed extruded from the family, unable to take part in reciprocal roles within the family, he had his interesting conversations elsewhere.

Overall, the participants seemed to have a heightened awareness of time, so much so that important actions and activities were often carefully measured and calibrated

against clock time and fragile body capacities. A dynamic working out was described that focussed on accomplishing meaningful activities where possible and, when necessary, giving into and adapting to the overwhelming effects of ataxia. Time was manifest in ambiguous and paradoxical ways: Bill, forced to focus on chewing and swallowing during mealtimes, seemingly trapped in the present moment but strangely out of step with from what was going on around him; Joan, clock watching as her physical capacities began to fail, seemingly annoyed not just at this change in herself but also in some sense at time itself (*'half an hour it's such a short time and very trying'*), and Susan with time pressing in on her, like a physical entity imposing limits on what she could fit into her day. Participants also spoke about the need for laborious planning that robbed them of spontaneity and freedom in the moment (*'I can't just go to the station anymore and just travel'*, Julia), as well as the everyday movements and actions that required careful calibration and attention (*'everything is much slower [...] the physical act of cutting meat, or whatever and then chewing it, making sure it's small enough so I don't choke'*, Jim). Harry spoke similarly, he squeezed in leisure pursuits and activities that were directed towards preserving bodily capacities between work responsibilities and whilst managing fatigue:

*Harry: 'It's not easy ... you run out of time. You get home at like 8 o'clock at night, go out on my bike for like quarter of an hour and then the standing frame. Go to bed by 9 o'clock, you know.'*

As discussed in chapter 6 (The Embodied Experience of Living with Progressive Cerebellar Ataxia), for the majority of participants, fatigue formed an almost permanent backdrop against which activities were accomplished, modified or abandoned. Hugh seemed to be immersed in a particularly difficult phase, whilst Scott, Graham and Joan also demonstrated perhaps that persevering was sometimes futile, and that managing also involved, at times, giving in, sacrificing or adapting activities to avoid adverse and distressing consequences.

Changes to the corporeal self, brought about by ataxia, altered the way in which time was lived and understood by the participants in this study. It seemed that the natural flow of time and the sense of lived time had been distorted and disturbed, it pressed in on meaningful activities rendering them difficult or even impossible. Quality time seemed to be snatched in very small chunks. However, despite these setbacks and difficulties, nearly all the participants derived a sense of satisfaction from the activities and interests they were able to pursue, albeit in the majority of cases in a modified and somewhat

strained way. This is not to deny the loss and sadness many also encountered when some activities were abandoned for good, as discussed previously with reference to Harry's account. Joan's experience could also be considered typical in this regard. Joan had been a dancer since she was small child:

*Joan: 'I'd had to stop dancing all together and that was very disastrous, cos we were ... we are a group of people, a lot of whom are on their own. We used to dance twice in a week. Virtually every Saturday there was a lovely dance and we'd all dress up. Travel quite a long way to get there and we'd share cars, and it spun off into lovely friendships.'*

Giving up dancing felt 'disastrous' to Joan. Not only had she lost a part of herself, her long established identity as a dancer perhaps, but she also seemed to miss the excitement and anticipation of dressing up, planning the journey, the thrill of travelling and dancing with a close group of friends. It seemed that the sense of occasion as well as the dancing itself had been lost. The change in tense was also interesting; initially Joan started talking about the group in the past tense but quickly adjusted to the present ('we were ... we are a group of people'). Joan was no longer a dancer but met up with the group socially. This seemed to have preserved a sense of belonging and close connection with cherished friends who shared a common interest, and as such perhaps helped Joan to retain an important link with her previous self. However, meeting up with these friends was also a threatened activity that Joan was in the process of thinking about and adjusting to:

*Joan: 'This little buggy will go in the back of the car. The problem is that [...] it was okay for me to lift in and out, it cuts down into four bits, time has moved on and I can't do that quite so easily. [...] perhaps if I can get motivated ... [...] if I got a car that was fairly tall at the back I could have a hoist to put the buggy in, then I would really get back to being totally independent from that point of view again.'*

The above quotation reinforced the interpretation that the pursuit of valued interests required on-going effort ('perhaps if I can get motivated') and adjustment in response to deteriorating physical competencies ('time has moved on and I can't do that quite so easily').

Similar to Joan, Julia referred to herself as a quilter in the present tense ('I'm a quilter'). Even though Julia could no longer quilt she still met up with the quilters and joined in, as far as possible, with their social activities. She had worked out a way of maintaining her creative interests through working with fabric and wool in a less intricate way and this

perhaps retained her sense of identity as a creative person and as a quilter. Furthermore as Julia had remained a social member of the group, perhaps in similar ways to Joan, this also fostered a sense of continuity and belonging: *'I'm part of the gossip'*.

#### **9.4.1 Summary**

Participants described modifying activities and interests where necessary to compensate for diminished capabilities, and to continue to meaningfully engage in the world as best they could on their own terms. Ataxia seemed to be viewed as having the potential to disconnect participants from others, to loosen the social threads that provided companionship and a sense of belonging. Adaptations were therefore made on an on-going basis and with respect to temporal considerations and uncertain bodily capacities. Fatigue and progressive disability shaped the extent to which participants could contribute and derive satisfaction from the activities they were most interested in. Working out ways of coping seemed hugely effortful. Sometimes with the support of others, and although not always possible, participants accomplished activities and by doing so held onto a preferred and valued sense of self that also deemphasised the salience of ataxia in their lives. Although some participants had to give up on or abandon some activities, they worked to preserve the friendships that usually accompanied them. Shared interests and being with others, even when no longer able to participate in the activity itself, seemed to provide a highly valued sense of continuity and social inclusion.

#### **9.5 Discussion**

This super-ordinate theme was divided into three sub-themes. The first explored the ways in which participants recounted a need to secure reliable sources of information outside of biomedical encounters, and to gain support from others with ataxia to offset feelings of isolation, confusion and abandonment. The second subtheme looked at the ways in which participants spoke about developing a philosophy to foster self-determination and to resist uncertainty and disruption. The final subtheme identified and discussed how participants saw their lives transformed as they struggled to adapt to loss and change whilst holding onto a sense of themselves and their connectedness to the things in the world (people, activities and ways of being) that were important to them. The experience of living with ataxia was portrayed in this theme as a struggle and an effort, and although participants described attempting to live with ataxia in a positive way, these attempts were by no means straightforward. Participants' descriptions did not

hide the pain involved, the continued effort required or the sacrifices that were made in order to construct their lives in a way that retained some sense of satisfaction and fulfilment. Loss was endured and the future was viewed uncertainly, both with hope about what could be sustained and accomplished as well as with caution for anticipated hardships and disappointments.

Running through these accounts was a common thread that involved connecting with others in a similar situation and retaining a sense of continued belonging to long-standing group memberships and close personal relationships. Being with others in a meaningful way whilst participating in a valued role or interest seemed to offset feelings of vulnerability and isolation. Other people (either similarly affected by ataxia) or members of a valued group (joined together on the basis of a common interest such as quilting) appeared to enrich the meaning of a particular interest, activity or pursuit. It was not simply the activity in and of itself that was important, but the deeper social contexts of the activity and the meaning it held for a particular person in a particular situation. In other words, these valued groups were not all about ataxia or providing support for people living with ataxia. Active engagement in meaningful activities and opportunities for reciprocity seemed to help preserve valued identities and contributed to sustaining a familiar and on-going sense of self.

These findings are not revelatory in the sense that others have identified similar issues with reference to the hardships people face when living with a long term condition, as well as the threats that are suffered to a person's sense of identity (Bury, 1982; Charmaz, 1983). However, the sense of dynamic working out, the constant adjustment and deployment of resources to accommodate symptoms such as fatigue and issues such as uncertainty, whilst, at the same time, safeguarding valued roles and a positive outlook, mirrors more recent work (Sanders et al. 2002; Reynolds and Prior, 2003; Reeve et al. 2010). Taking this dynamic perspective into account, the landmark theory of biographical disruption as a means of encapsulating the experience of chronic illness (Bury, 1982) has been taken as the point of departure for this discussion. This theory will be critically interrogated with reference to other work and more recent developments in understanding the lived experience of long term illness.

Bury's (1982) now classic formulation of chronic illness as 'biographical disruption' has been much discussed and critiqued since its publication, nonetheless it is argued here that this concept retains validity with reference to the accounts of the participants in the present study. Bury (1982:174) identified that an incomplete medical understanding of a person's illness or condition left those with such a condition dependent upon their own

'stock of knowledge and biographical experience'. Furthermore, Comaroff and Maguire, (1981:119) proposed that those who lived with illnesses where explanations and solutions were not readily offered, found themselves 'especially bereft'. Under such circumstances, Bury (1982) suggested that people attempt to fill gaps in their understanding by looking for more comprehensive explanations and sources of information. Critically Bury (1982:174) claimed that once such knowledge was acquired it was then necessary to integrate it with a person's 'total biography'.

This search for and subsequent interpretation of knowledge or information in light of one's own particular circumstances and contexts could be traced in the accounts of participants in the present study, and was perhaps most strongly identified in Graham's account: *'how's that informing me, my situation?'* It was also a feature in others' accounts. Subtheme 1 identified a need to seek out information that could be used to complete or at least develop the participants' understanding of their condition and to reconcile this with what they understood from their own experience. In turn, as with the participants in Bury's (1982) study and with reference to more recent work about coping successfully with multiple sclerosis (Pinson et al. 2009), knowledge that was integrated and thus situated within a personal context seemed, at least partially, to dispel uncertainty and, ultimately, provided a basis upon which meaningful lives could be lived.

Bury (1982) also proposed that the onset of chronic illness instigated a profound re-evaluation of a person's future plans, hopes and expectations. Part of this reassessment included the anticipation of hardship and loss more usually seen as a far off possibility in one's own life or, at a distance from the self, in the misfortune of others. Participants in the present study identified similar concerns in subtheme 2 (Taking a Stand: personal philosophies for living with ataxia) and 3 (Finding a way to preserve valued roles and interests) and, either directly or obliquely, referred to anticipated disruptions that, rather than being in the far future, seemed to press in on them, a source of almost constant worry or concern that had to be resisted and managed (*'otherwise electric wheelchairs here we come, you know'*, Harry). In the face of these disruptions, Bury (1982) proposed that individuals mobilised resources (cognitive, material and social) in order to repel the intrusion of chronic illness upon their lives. Furthermore, Bury (1982) argued that a person's outlook or ability to manage might also depend on their ability to sustain friendships and reciprocal relationships. Similar to the participants in the present study, Bury did not suggest that coping mechanisms evolved without thought or hardship: 'The erstwhile taken-for-granted world of everyday life becomes a burden of conscious planning and expedition' (1982:176). Again, these words resonated with the experiences

recounted by the participants in the present study. The meticulous and wearisome planning and on-going adjustments that were made to ordinary activities of daily life were strongly articulated in the majority of accounts.

In his evaluation of Bury's (1982) concept of biographical disruption, SJ Williams (2000) offered a revision of the view implied in Bury's (1982) thesis that biographical disruption shattered taken for granted assumptions about the body, self and world. Drawing on the work of Pound et al (1998), Williams proposed that the concept of biographical disruption failed to account for the ways in which illness may already have been a feature of a person's biography. Within the context of on-going hardship, the emergence of a new event may not be considered particularly disruptive. As discussed in chapter 2 (Understanding the Subjective Experience of Long-term Illness), Pound et al (1998) found that their elderly participants, having lived through adversity in the war, seemed to accept their stroke as part and parcel of a life run though with suffering and hardship. It was argued by the authors that, in this context, a stroke had less potential to be biographically disruptive. In the present study several of the participants had also lived through adversity such as bereavement, unemployment, marriage breakdown and previous illnesses. However, in contrast to the accounts of elderly people living with stroke, none of the participants (except perhaps Harry, who had lived with ataxia since his late childhood) seemed to consider the disruptions they experienced in living with ataxia as part of their anticipated life trajectory. It does not seem to be too great a step therefore to suggest that for most of the participants in the present study, and only within their particular contexts, ataxia could be understood as imposing or at least risking some sort of estrangement with their sense of biographical continuity.

Developing his critique and with reference to the work of Carricaburu and Pierret (1995), SJ Williams (2000) suggested that in some cases illness onset conferred a sense of biographical continuity or reinforcement rather than disruption. This was not found to be the case in the accounts of participants in the present study. The reason for this may lay in the conceptualisation of biographical reinforcement which appeared to be very specific to the circumstances of one group of participants. HIV-positive men who were infected as a result of haemophilia described already living their lives around an anticipated illness trajectory. It was suggested that under these particular circumstances a HIV-positive status confirmed or reinforced their biographies rather than disrupted them (Carricaburu and Pierret, 1995).

Finally, SJ Williams (2000:61) suggested, albeit cautiously and rather speculatively, that biographical uncertainty was a regular and not an unanticipated feature of late modernity in which there is a 'never ending cycle of biographical appraisals, revisions and improvements'. Whilst this might be the case from a broadly sociological perspective, and although this may not be an intentional outcome of such speculation, the grouping of illness experience within a more general concept of late-modern existential angst, seems to fail to acknowledge and respect the profound disruptions described by the participants in the present study.

One of SJ Williams' central and concluding arguments lay in asking for a more cautious application of the concept of biographical disruption to the findings of research into the experience of illness. In particular he called for careful attention to be paid to 'meaning and contexts' and 'the manner in which identities are threatened or affirmed' (Williams, 2000:61, 62). The present study, through the cautious application of IPA, carefully teased out the highly situated and context dependent ways in which participants described their experiences of ataxia. Steps were taken to prioritise the participants' accounts over and above the theoretical constructs apparent in the literature. Nonetheless the critical features of Bury's (1982) concept of biographical disruption resonated with the findings presented in this chapter but, as perhaps anticipated by SJ Williams (2000), in ways that were particular to participants' circumstances and biographical history.

G Williams' (1984) work on narrative reconstruction could be read as a continuation of Bury's 1982 thesis (Lawton, 2003). G Williams predicated his ideas upon his participants' sense making about the causation of illness. However, its central message has resonance with the accounts of participants in the present study and pre-empted Bury's (1991) calls for a shift away from focussing purely on the problems people face in living with long term illness. G Williams' (1984:197) ideas about narrative reconstruction suggested that people living with long term illness attempted to 'reconstitute and repair ruptures between body, self and world by linking up and interpreting different aspects of biography in order to realign present, past and self with society'. Realignment, in this sense, was understood as the means by which people attempted to reconstitute their lives in ways that were meaningful to them, such that they retained some sense of order and coherence with their past and present selves. Once again this idea that people living with long term conditions expended effort on working out ways of holding on to the parts of their lives that gave them a sense of continuity and order, strongly resonated in each of the subthemes presented in this chapter. Reflecting on this and other work, Bury

(1991) encouraged researchers to redress what he saw as an imbalance in the literature that was tipped towards understanding illness as a master status; the passive acceptance of a personal tragedy. Bury (1991) argued that the diversity of experience should be explored and, where possible, examples might be documented where a hopeful future, or one at least that was not wholly burdened by the impact of illness, had been fashioned and articulated. It is towards these considerations that this discussion now turns.

A body of work, the conclusions of which resonate with the accounts of the participants in this study, has suggested that an uncritical application of the concept of biographical disruption to understanding the influence of illness experience in an individual's life is problematic. For example, over time, people living with long term conditions have been found to construct lives that are continuous with their established biographies by retaining connections to valued roles and occupations, minimising the disruptive effects of illness, and by focusing on the parts of life that for them constitute a life of good quality (Pinson et al. 2009; Faircloth et al. 2004; Reynolds and Prior, 2003; Sanders et al, 2002; Moch, 1998; Lindsey, 1996; Lundmark and Bränholm, 1996). As discussed in chapter 2, Faircloth et al (2004:256) introduced the concept of 'biographical flow' to reflect the processes by which people living with long term health conditions constructed their lives in ways that integrated their illness within an on-going biography.

Reynolds and Prior (2003) specifically explored experiences that were considered by women living with multiple sclerosis to provide them with a sense of life satisfaction. The women who participated in this study identified a number of positive and beneficial strategies that enabled them to preserve participation in valued roles which in turn contributed to a life that was considered as having good quality. The findings from this work possess a particular relevance for the findings offered from the present study. As with the present study (subtheme 3), it was specifically the roles, the areas of life that held deep meaning through their close intertwining with a person's past, present and future, as well as through their connections with significant others, that, taken as a whole, conferred a sense of coherence, continuity and well-being. Reciprocity, rather than one way support, was particularly valued and meaningful. The findings from the present study particularly emphasised the importance of connecting and belonging to preserving a person's sense of self. The need to belong is considered a fundamental human motivation (Baumeister and Leary, 1995). It is generally fulfilled (for people with and without disability) by the development and preservation of interpersonal relationships, such as those constituted in the roles and activities that people living with

ataxia seemed to work so hard to retain, including relationships not based purely on illness but on shared interests.

More recently however (and as discussed in chapter 2), Reeve et al (2010) argued that examining illness strictly through the lens of biography provided an inadequate foundation for understanding individual lived and specifically embodied experience. These authors asserted that, whilst theoretically meaningful, the biographical concept, underpinned by a reflexive model of the self, assumed that identity is constructed through a cognitively driven narrative. Research with people living with terminal cancer identified narratives of both disruption and flow but stressed that the participants' efforts were focussed on 'living their daily lives' rather than maintaining a meaningful narrative (Reeve et al. 2010:190). In ways that resonated with the findings of Reynolds and Prior (2003) and with reference to Carel (2007), it was suggested by Reeve et al (2010:190) that their participants emphasised a 'functional' and 'embodied' rather than a 'reflexive' account of the self in fashioning meaningful ways to live with long term illness. Furthermore, for Reeve et al (2010) it was the physical and emotional concerns (e.g. fatigue and depression) rather than a loss of meaning per se that determined an individual's capacity to maintain continuity in their everyday lives. Embodied concerns and a focus on continued participation in meaningful activities also seemed to be a primary concern of participants in the present study.

Similarly, Reynolds and Prior (2003) identified the complex ways in which participants in their study attempted to manage their lives in positive ways whilst coping with the vicissitudes of life with multiple sclerosis, findings that were also reflected in subtheme 2 and 3 of the present study. Other authors identified similar issues in terms of living with multiple sclerosis (e.g. Pinson et al. 2009) but also other long term conditions such as chronic pain (Ong et al. 2011; Grime et al. 2010; Richardson et al. 2008; Sanders et al. 2002). Taken as a whole, these authors' work suggest that biographical disruption as well as biographical repair and continuity remain valid concepts with which to understand the lived experience of long term conditions such as multiple sclerosis and chronic pain. However, the complex co-existence of the encouraging as well as the more distressing aspects of living with an uncertain but progressive condition were powerfully revealed by Reynolds and Prior (2003) and Reeve et al (2010). Furthermore, the present study demonstrated, for the first time, how these concepts may resonate with the experiences of people living with progressive cerebellar ataxia.

## 9.6 Conclusion

This new work deepens the understanding of the concept of co-existing biographies; a familiar biography intertwined with a disrupted biography, with reference to the lived experience of progressive cerebellar ataxia. It also strengthens the claims made by Reynolds and Prior (2003) and Reeve et al (2010) that an individual's capacity to construct a valued life in the face of chronic illness, in other words their ability to '*manage it*' (Joan), depends upon the highly situated and contextualised identification and mobilisation of physical, cognitive, emotional, and social resources. In turn these resources, when available, help to preserve valued roles and activities, and it is this preservation of roles which seemed to dominate the concerns of the individual participants in the present study. This is not to say that retaining meaningful roles and activities, preserving a valued identity and trying to make sense of ataxia as a health condition was a straightforward process. Cognitive strategies such as reappraisal may be effective at least in part because they motivate action. However, for participants in the present study, positive life experiences and meaningful information and support seemed to be wrested and shaped from in amongst the more distressing aspects of life with ataxia. Persistent endeavour and enterprise were not always enough and at these times participants acknowledged that the more negative consequences of life with ataxia could, at least temporarily, take control and overwhelm them.

## Chapter 10

### Super-ordinate Theme 5

**Quotation:** *'It makes me feel better that I'm actually doing something'* (Ted)

**Description:** Exercise: a multifaceted contributor to managing life with ataxia

#### 10.1 Introduction

Exercise and physiotherapy were specified in the research questions therefore participants were explicitly asked to talk about their experiences of these topics during the interview. This super-ordinate theme focuses on the role that exercise played in participants' lives and the contribution that exercise seemed to make to managing life with ataxia. Participants' experiences of physiotherapy are also considered within this theme. This was because it seemed that physiotherapy was partly understood in terms of exercise and therefore participants' perceptions of physiotherapy and exercise were closely intertwined. Physiotherapy also appeared to symbolise a hoped-for resource for learning about and living with ataxia that went beyond straight-forward exercise prescription. The findings discussed in this chapter are aligned to those detailed in chapter 9 because they also convey participants' attempts to gain a sense of control over the impact of ataxia in their lives.

The researcher was aware that the interview and subsequent analysis of material that referred to physiotherapy would be conducted through a particular lens focussed by her clinical experience as a physiotherapist. It was apparent that this pre-understanding may influence the direction and focus of the research. Using the concept of hermeneutic reflection (Finlay, 2003a; Shaw, 2010) the researcher identified a risk that her professional affiliations and loyalties may blind her to negative accounts of physiotherapy and/or physiotherapists. This view initially led the researcher to over-compensate by interpreting participants' accounts in an overly negative way. Rather than adopting the attitude of 'thoughtful vigilance' (Dahlberg et al. 2008:97) described in chapter 1, the researcher allowed her reflection to form new prejudices that got in the way of the data and prevented the accounts from speaking for themselves. This situation was only resolved through critical questioning of the analysis driven by further hermeneutic reflection.

Two subthemes convey participants' experiences of exercise and physiotherapy. The first focuses on exercise and the multiple roles it played in helping participants live with ataxia from a physical as well as a psychosocial perspective. The second subtheme

examines the ways in which participants understood and experienced physiotherapy. It considers the variety of experience recounted by participants, the beneficial as well as the more negative features.

## 10.2 Subtheme 1

**Quotation:** *'it does make you feel good and you've got an awful lot of control over things'* (Scott)

**Description:** Exercise as a means of seeking control and sustaining a positive sense of self

Caspersen et al. (1985:128) defined exercise as 'physical activity that is planned, structured, repetitive and purposive'. Sporting and conditioning activities fall into this classification as do occupational tasks and other daily physical activities that are regularly performed in the manner described above. Whilst the first part of this definition remains valid the second part is contested (Sebire, 2009). This is because 'purposive' refers to exercise that aims to improve or maintain one or more components of physical fitness such as muscular strength and/or cardiorespiratory endurance (Caspersen et al. 1985). It suggests that the exclusive aim of exercise is the achievement of goals concerned solely with improving physical performance (Sebire, 2009). However, the accounts discussed in this sub-theme suggest that the meaning of exercise was much more complex and went beyond simple inferences about improving bodily function.

All participants had taken part in some sort of physical exercise since being diagnosed with progressive cerebellar ataxia (Table 10.1 pp. 221). The type of exercise was selected by the participant and not prescribed by a physiotherapist, except for particular home exercise programmes. At the time of interview, three participants had stopped exercising either due to pressure of work (Ted), acute illness and fatigue (Hugh) or through being unable to exercise independently at home (Bill). For the majority of participants ( $n = 10$ ) exercise fulfilled multiple functions that were not simply restricted to attending to the impaired body. This subtheme looks at the ways in which participants described exercise and their reasons for taking part in exercise based activities.

**Table 10.1 Physical Exercise Undertaken by Participants (n = 12)**

Activity	Participants	Number
Home exercise programme – prescribed by a physiotherapist	Toby, (Bill)	2
Home exercise programme – self-devised or adapted	Julia, Susan, Harry, Joan, (Hugh)	5
Swimming	Stella, Toby, (Ted), (Hugh)	4
Gym	Jim, Scott, (Ted)	3
'Exercise on prescription' – gym	Stella, Jim	2
Yoga class	Joan	1
Pilates class	Joan	1
General exercise class	Julia	1
Hang-gliding	Harry	1
Adapted cycling	Harry	1
Water sport	Scott	1
Team sport	Graham	1

(Names in brackets mean that these participants were no longer doing this activity at the time of interview)

Julia's account of the meaning of exercise has been used to introduce this subtheme. For Julia, exercise fulfilled an important need to maintain a valued occupation:

*Julia: 'Every morning I walk within the building [...] the walking is 500 meters but then there are 140 stairs as well. [...] I must be getting a kick from it because I really enjoy it.'*

*Interviewer: 'Brilliant, and why do you do it?'*

*Julia: 'To keep my mobility. And the stairs and ... if I can't do them then I won't be invited to babysit. [...] It's too much to lose.'*

Julia described undertaking a regular and purposeful exercise routine. Not only did she describe this activity as helping to preserve her ability to manage stairs and therefore look after her grandchildren, it also seemed to provide her with a sense of achievement ('500 meters', '140 stairs'). She knows the exact number of stairs and the exact distance she walked. This detail signified the effort perhaps, as well as the challenge that doing this sort of exercise entailed. Counting may also have acted as a sort of benchmark. It not only measured how far she walked and how many steps she climbed but also confirmed perhaps that she was still the kind of person who could walk this distance and climb this many stairs. Thus it seemed that although Julia focussed on maintaining her grand-mothering role, other factors perhaps also helped to sustain the regular practice required in order to hold onto this role. From a social perspective other residents looked out for her and acknowledged her efforts ('Yes, I'm on my patrol they call it') and, as she explained later, she seemed to gain some sort of psychological or emotional boost from undertaking this sort of exercise:

*Julia: 'I think ... is it adrenalin, you get when you ... the walkers, the marathon runners ... I think I might be getting a bit of ... is it heroin or something ...? [...] I think I'm getting some sort of feedback from it.'*

In the above quotation, it is interesting to note that Julia used the example of endurance athletes. Perhaps this is how it felt for Julia; her exercise routine was comparable to completing or training for a marathon. There was also a glimpse of the effort involved and, because of this added strain ('500 meters', '140 stairs'), the successful completion of this daily task perhaps provided an additional sense of achievement and positive feedback.

Julia described how she had devised her own exercise programme. It was put together by Julia but members of her family had helped her develop it by measuring the distances involved, calculating the number of steps, accessing the music Julia had chosen to accompany the exercise and uploading it onto an MP3 player. Julia's exercise routine was therefore portrayed as a family concern and represented as an investment of collective time and effort. In this sense and in addition to the continued achievement of her goal as a marker of success, Julia also perhaps retained a sense of commitment to, and ownership of the programme that may also have been important in maintaining her perseverance.

Julia's physiotherapist had also prescribed some stretches which Julia had incorporated into her daily routine: '*After the first corridor I can stop in private and do my stretching and then go on*'. Again, it is interesting here that Julia does her physiotherapy '*in private*'. This suggested perhaps that, through being medicalised, Julia believed there might be something embarrassing or uncomfortable about doing these stretches in public. Whilst her feats of endurance seemed to be genuinely celebrated, the prescribed stretches were hidden away. A deeper interpretation might suggest that Julia thought of the stretches as in some way remedial, a clear indication that something was wrong and in this sense a projection of the self as in some way vulnerable or frail. Julia perhaps resisted this view of herself or at least preferred to hide it from others.

Overall, and importantly for Julia, the focus of her self-devised exercise routine was the maintenance of a valued role as a grandmother but it also perhaps worked to preserve a capable and independent sense of self in the face of living with a progressive neurological condition. The exercise was in itself sustained by a number of emotional, social and psychological factors. Julia's account therefore pointed towards an understanding that exercise fulfilled multiple roles and purposes that were not limited to

simply preserving physical capabilities. As the next section demonstrates, exercise contributed in several complex ways to preserving a positive sense of self for other participants in the study.

Several participants spoke of the importance of exercise as a means of doing something and feeling good i.e. “doing something rather than nothing”. Although the benefits of “doing” were described in terms of feeling better in oneself or about oneself, there seemed to be something deeper to understand that went beyond an interpretation that exercise simply conferred psychological benefits and / or was only concerned with the management of symptoms. For example, Scott said of exercising in the gym *‘it does make you feel good’*, and Graham; *‘it’s much better. Physically, mentally you know... whatever level you want to put it on,’* and Ted; *‘It makes me feel better that I’m actually doing something’*. Whilst reflecting upon the psychological benefits of exercise, these participants, perhaps in response to Western social forces that value industry over indolence, might also have been resisting passive formulations of the self. In addition, these participants perhaps saw exercise as a means of standing firm against a negative sense of self in similar ways to Harry, as described in the previous chapter: *‘it’s so easy to sit at home, watch telly and wondering about the next episode of ‘EastEnders’*, and Toby:

*Toby: ‘Well if I hadn’t done any swimming or physio and I’d just... like some people if they’ve been diagnosed, [...] because if I’d thought ‘Oh I’ll never work again’, sit at home in a chair watching television, stuffing crisps, drinking pop, putting the weight on, exacerbating the problems I’ve already got, and it’s a downward spiral.’*

For these participants, exercise could be understood as a way of gaining a sense of agency in a situation where there is no cure or symptomatic relief. Exercise was not undertaken as a means of curing ataxia, it was not some naïve enterprise where exercise was thought to succeed where medicine had failed. Taking part in exercise, *‘doing something’ (Ted)* helped maintain a positive outlook. Jim’s account captured the complexity of this situation when reflecting upon his experiences of going to the gym:

*Jim: ‘it’s had a noticeable difference on my calf muscles, although they’re wasting away, so I can’t stop that, they do feel stronger. [...] And it gives you more confidence and you just feel better for doing something. So I’m keeping that up. [...] It makes a difference - one, in the way that you feel and two, your general sort of attitude. It just makes you feel better and your mind feel better physically. So I don’t know if it’s doing anything but just the fact that I can do it and I am doing it, does make a difference.’*

In the quotation above Jim not only pointed towards the psychological benefits of exercise, the positive effect on his sense of well-being (*'It just makes you feel better and your mind feel better physically'*), but it was also possible to glimpse two other important features of exercise. First, Jim did not seem to see exercise as a cure (*'they're wasting away, so I can't stop that'*), he suggested that exercise made him feel stronger (not less ataxic) and that feeling gave him confidence. Secondly, there was just a hint in this text that exercise gave Jim a sense of competence or mastery, it was something within his power that he could do that was not completely overshadowed by ataxia: *'just the fact that I can do it and I am doing it, does make a difference.'* The sense of achievement, underlined, again seemed crucial here. Scott and Toby spoke similarly:

*Scott: 'If you're doing it on a regular basis so you can monitor exactly how you're going, your muscle strength and tone and posture all improve and it does make you feel good and you've got an awful lot of control over things. It doesn't stop you from falling over if you turn around quick but it makes every other thing that's possibly going downhill get back into some resemblance of being in the best condition it can to cope with what you've got.'*

*Toby: 'It makes my legs [...] the muscle tone, they're far more rigid, your feet feel planted on the floor firmly. I'm not saying you still don't veer, whatever, from side to side, lose your balance momentarily – you do – but you're far more in control.'*

Again, Scott and Toby, like Jim, described feeling stronger or more stable as a result of exercise and this feeling seemed to give them confidence and an improved sense of agency. Both acknowledged that the ataxia had not improved (*'It doesn't stop you from falling over'*, Scott, *'I'm not saying you still don't veer'*, Toby) but through going to the gym or swimming they perhaps felt better equipped to cope with its effects.

Scott was also involved in water sports. He explained that he did these sports not to reverse the effects of the ataxia but *'as the best way of managing what I've got [...] as some kind of jolt to my balance mechanism, saying 'you've still got to do some work, you can't just sit there and be shy', just to keep it working.'* This kind of anthropomorphism possibly helped Scott develop a positive relationship with the ataxia, and in this way it was not some abstract concept or external thing that he had no control over. Similarly, for the majority of participants exercise seemed to provide a sense of purpose and well-being, not a feeling that they were able to gain complete control over their condition but at least some sense that they were not rendered powerless by its effects.

For Scott and Graham, out-of-doors activities were described as helping to reduce feelings of isolation and keeping depression at bay:

*Scott [with reference to water sports]: 'The psychological effect of going outside and being in a different environment stopped me relapsing into depression which is another controller to get out.'*

Scott also seemed to suggest that he felt stuck at home and needed strong incentives ('controllers') to get out of the house, exercise seemed to provide this sort of motivation.

*Graham: 'I understand that's one of the wider aspects of disability that it is very isolating. [...] I'm not very good at fitness regimes, I've tried to do the gym but it's not for me. But I've started playing [a sport for disabled people] this year so that's ... I mean more than anything it's something I have to think about, you know. It's a social activity but it also has a physical aspect to it.'*

Playing a team game perhaps stopped Graham dwelling on the more negative experiences associated with living with ataxia ('*I mean more than anything it's something I have to think about, you know*'). For Scott and Graham, in addition to the important social benefits of getting outside and meeting with others who shared a similar interest, it also seemed important to convey a sense that they were achieving something by doing these activities, accomplishments that the researcher would recognise and respect. Scott had passed his '*one star*' and described himself as '*gradually improving*', and Graham seemed quite proud of the fact that he played in a national league and was seen as a county player; '*it's a national league, a county league, so I play for [a particular county]*'. These activities seemed rewarding in themselves but also contributed to a sense of self-worth which may have helped Scott and Graham cope with the losses that were associated with living with progressive ataxia. Furthermore, these activities marked a return to sports that both Scott and Graham used to do before they developed ataxia, and this perhaps provided a strong link with the past; a connection to their biographical roots that helped to sustain a familiar and valued sense of self.

Finally, Harry enjoyed the feeling of flying (a type of hang-gliding) because it gave him a sense of freedom and equality; of being judged on his own terms:

*Harry: 'For me it's the most fantastic feeling, because you've got full movement, you're not reliant on the gravity thing. Pain in the arse. You're equal to everybody else. When you're out there nobody can see the wheelchair.'*

The above quotation might suggest that Harry valued his sport because it gave him a sense of embodied freedom that he was unable to achieve on land. This being so, Harry's account also prefigured the main theme of chapter 7 which concerned the ways in which participants encountered and were, at times, able to overcome and cope with social discrimination as part of their experience of living with physical impairment. However, flying also seemed to fulfil an important part of sustaining Harry's preferred sense of self as someone who was not diminished, inhibited or defined by his ataxia or his wheelchair use.

### **10.2.1 Summary**

Participants' accounts suggested that it would be a mistake to understand their engagement in physical activity in simple unitary terms, as entirely concerned with some inward looking project about the control of bodily impairment. Exercise seemed to be much more about being in the world; meaningful projects and authentic involvement with others; health promotion perhaps in the broadest of senses. These diverse activities, ostensibly concerned with the body, reduced social isolation, sustained valued occupations, preserved identity, countered depression, helped to overcome stigma, and generated a sense of well-being and control. The particular significance and importance of each of these phenomena varied for each participant.

### **10.3 Subtheme 2**

***'You get about 6 weeks and then you're discharged and sent home to do your exercises on your own' (Stella)***

**Description: Physiotherapy – at times overly one-dimensional and inexpertly focussed on the impaired body**

The following subtheme explores participants' encounters with physiotherapy services and physiotherapists, the benefits as well as the disappointments, and the extent to which physiotherapy fulfilled its expected roles. With reference to the previous subtheme, all participants understood exercise as a potentially positive influence in their lives and looked to physiotherapists and physiotherapy to fulfil a similar role. Overall,

participants presented a rather a mixed picture of physiotherapy where positive experiences coincided with frustration and dissatisfaction.

Harry's experiences highlighted key issues raised by the majority of participants and several quotations from Harry's account have therefore been used to introduce this subtheme. Extracts from other accounts demonstrate the extent of the shared experience and deepen the discussion. Unlike other participants, Harry had built up a very good rapport with his physiotherapist over many years:

*Harry: 'I've been seeing [my physiotherapist] for years. [...] I would say that I would be a hell of a lot worse, a hell of a hell of a lot worse without physio'.*

Physiotherapy was portrayed as the only healthcare provider that had given Harry any sense of continuity and commitment, as whilst other services had stopped sending follow up appointments, '*physio never stopped*'. Furthermore, Harry's physiotherapist seemed to be able to offer a flexible service which suited Harry's particular needs:

*'I try to go there once every ... no two or three times a year, but usually in the winter. If I'm not doing ... they will try and have me back if I deteriorate, that's the worst time of year for me. [...] If I need to see her I can go to see her anytime. [...] I've got her e-mail address'.*

Following a debilitating acute illness, for example, Harry looked to physiotherapy to support his recovery:

*'I was really run down. [...]. I would get dressed in the morning and be worn out. Then wheezing during the day. And I went back to physio and through the exercise they taught me and what they taught me, the effects of everything and what I could do, what extra I could do, you know, it was a new lease of life.'*

Harry seemed to suggest that by offering '*a new lease of life*', physiotherapy not only addressed his physical impairments but also conferred new prospects for living. Physiotherapy therefore symbolised renewal and relief from the perhaps depressing place Harry found himself in up to that point. Harry also saw his physiotherapist as instrumental in making sure that he was prescribed a lighter, less tiring wheelchair ('*And that was fantastic, that was ... that gave me ... I could stay up late, you know, I wasn't ... [...] and that made a huge difference*'), and also, if necessary, she visited Harry at home ('*She came around to the house as well*').

Harry's experiences of physiotherapy seemed uniquely situated to his particular circumstances and none of the other participants described a comparable level of connectedness and trust. He touched on aspects highlighted as important in other participants' accounts, notably the high value placed on continuity of care, as well as flexible and responsive service provision. However, Harry was also frustrated and disappointed by what he perceived as limited resources and a lack of knowledge about effective treatments:

*'There is no book. There's no guide. [...] There's no ... and it's just like ... loads of times they [physiotherapists] call us like 'Been trying to work out exercises'. Cos see there's no ... there's nothing on the web or ... you know, no book of ataxia sufferers ... exercises for ataxia. Nothing like that. [...] I would say there needs to be more instruction. I mean me and the physios, basically it's trial and error.'*

In saying *'I mean me and the physios, basically it's 'trial and error'*, Harry seemed to allude to the common position of partnership working, but for Harry both partners were working in the dark. Harry seemed horrified that there was no manual of exercises or stock of knowledge for physiotherapists to draw upon. In his experience, physiotherapists compiled untried exercises which involved as much failure as success. Harry's experiences in this regard, were recounted by the majority of participants (Table 10.2 pp. 229).

**Table 10.2 Inexpert and Impairment Focussed Physiotherapy (n = 8)**

Participant	Extract	Page: line number
Bill	<i>'I know more about it than they [physiotherapists] do, there's something wrong there.'</i>	10:45
Toby	<i>'If GPs aren't aware of it, what chance have the neuro physiotherapists'</i>	17:11
Harry	<i>'I've been asking different things about exercises [...] and she's been like 'don't know''</i>	18:27
Susan	<i>'I'm not sure that she [physiotherapist] wasn't thinking more of a stroke victim'</i>	13:33
Julia	<i>'The physio couldn't separate me from MS in her mind'</i>	17:6
Toby	<i>'[at the reassessment] She [physiotherapist] didn't ask me to do those [home exercises] or show her what I was doing'</i>	14:27
Stella	<i>'I felt they had not much idea about my condition or how to deal with it'</i>	2:9
Bill	<i>'I've got little kind of confidence in it [physiotherapy] really'</i>	7:6
Hugh	<i>'Management, they're so much in debt, just trying to save every penny, they don't care where it [physiotherapy] comes from, anybody'll do'</i>	15:11
Jim	<i>'We talked about exercises for your legs [...] they basically said 'well there's nothing we can do'. And I thought well hang on, you're a physiotherapist there must be something you can do'</i>	18:42
Harry	<i>'The hydrotherapy pool, they've shut it down, turned it into an office'</i>	29:24
Toby	<i>'She could check my centre of balance or how I was [...] but when I went to the physio department the machine was still broken'</i>	14:7
Stella	<i>'They just don't have the staff I suppose and the knowledge of my particular problem'</i>	18:22
Stella	<i>'Because of the pressure on their services ... mind, the gym was empty most of the time, I could have gone in'</i>	15:18

Similar to Harry, Julia's experiences of physiotherapy were also generally positive. She seemed to value physiotherapy as a resource, for suggesting practical ways of managing:

*Julia: 'There were things I was doing like closing myself up, putting my hands in my pockets when I walked and the physio showed me that I balanced much better with my hands out. And with a backpack in fact because I was leaning forward, she advised me to get a backpack, so I wasn't coping with a handbag or anything. And that pulled my shoulders back and made it better.'*

However, also similar to Harry, Julia perceived regular reassessment as important, preferably with a physiotherapist whom she had met previously and therefore perhaps knew her circumstances and did not need to ask the “same old questions”:

*Julia: ‘I do think you need to go back every now and then just to be checked over [but] the physiotherapists change every six months’.*

In contrast to Harry’s experiences, half the participants perceived shortcomings in service provision as well as the physiotherapists’ adherence to a particular type of service model. Short interventions which mirrored acute services (ranging from one- off appointments to sessions once a week for six weeks) were followed by the prescription of home exercises. These were easily forgotten or put aside, and were experienced as doing little to address the other important roles of exercise outlined by participants in subtheme 1. Susan’s account exemplified the difficulties expressed by some participants with reference to the prescription of a home exercise programme:

*‘They tend to send me home with a list of exercises that I can’t actually do. [...] I lay on the bed to do the exercises and I think ‘I’d rather have a little sleep. [...] Being tired all day makes it difficult to discipline yourself to do those things [home exercises]. That’s why I would rather go there more often and go through them with them, cos I haven’t really been doing what I’ve been asked to do at home.’*

In contrast to the positive feelings associated with participants’ accounts of exercising in a general sense, Susan’s experience of home exercises as prescribed by a physiotherapist, seemed to be overwhelmingly negative. Not only was she unable to do them, but they seemed to emphasise rather than diminish her physical difficulties as well as exacerbating her fatigue. She also described her physiotherapist as concerned with measuring improvement which meant very little to Susan:

*Susan: ‘She [the physiotherapists] usually has a chart that she goes through and she scores me. And some physios ask you to do something and then say ‘I think you could probably do a bit better’ and ‘try again’ and they get your score up and then they say to you ‘That’s was wonderful, your score’s higher.’ And I think that’s what you would do to a stroke victim to encourage them to make it better. In my case I want it to be true to what’s happening to me.’*

Susan did not describe exercise or physiotherapy as a means of providing tangible or measurable improvements; she was, it seemed, just hoping to preserve her independence as long as possible, *‘to maintain my mobility’*. Living with a progressive

condition she was not expecting her score to improve and in this sense it seemed that what Susan was looking for from physiotherapy was not aligned with the model of care she experienced. Susan perceived little benefit or sense of achievement from the few exercises she was able to manage at home which might explain why she had been unable to persevere. In Susan's experience, her request to see a physiotherapist more regularly was met with indifference:

*Susan: 'They give you these exercises and then they say 'I'll phone you and see how you're getting on'. Well I would much rather that I could go there ... and I've said that to them ... [...] And they say, 'Well it's not really necessary'. So I don't feel that I'm getting as much as I could.' [...] 'I'm really disappointed that there isn't continuity there.' [...] 'It's basically the lack of continuity of one physio and the opportunity to go more frequently for that if I want. That's what I'm not getting.'*

Susan seemed to perceive that the balance of power in this situation was tilted in favour of the physiotherapist. It was the physiotherapist who would make contact and arrange follow up appointments if they felt it was necessary. The rigid application of a "one size fits all" model of service seemed to offer little to Susan who failed to fit the mould. Susan emphasised her commitment to exercise, explaining that she had brought a treadmill to try to strengthen her legs but also stressed that she was looking for a slightly more "hands on" approach. She highlighted the importance of regular and frequent visits to the physiotherapy department, a familiar face and some feedback and advice; physiotherapy that was not only tailored to her ataxia but also to her as an individual.

Graham, Harry, Julia, Stella and Scott identified similar issues and, like Susan, they stressed the value they placed on establishing a rapport, or a sense of connection, with a physiotherapist:

*Stella: 'I've requested various physiotherapies, which you get about 6 weeks and then you're discharged and sent home to do your exercises on your own [laughs]. And I keep going back and requesting more physiotherapy and eventually I've got to neurophysiotherapy [...] Again, I've been sent home to do my exercises. She did say that if I felt I needed help or I found the exercises easy and needed more to push me a bit, then to get back in touch with her [...] So she hasn't completely discharged me, but I have no more appointments.'*

Graham, who generally spoke of physiotherapy in positive terms, perhaps best summed it up:

*Graham: 'I was given quite a substantial amount ... well six exercises to do. And the thing about that is it's quite easy to do when someone's asking you how you got on, but over time you think ah, I'm not going to do that. And so you slip back again and so it's the continuity that I found useful as much as the physical improvement if you like.'*

Scott spoke similarly: *'an assessment every now and then so you can go and bend somebody's ear [laughs] and they can say 'well try this', that might be helpful as well.'*

Graham's experiences of physiotherapy differed from the other participants in that he was offered outpatient physiotherapy over a longer period (20 weeks). Although he appreciated the exercise, he stressed the importance of the sessions for developing a lasting and supportive connection with physiotherapists because, as he explained later in his account: *'you're not dealing with ataxia on your own; somebody else is actually taking a bit of an interest.'* This willingness to listen and empathise seemed to be highly valued by the five participants who directly addressed this topic in their narratives but with reference to Susan's account, it could also be suggested, with some caution, that, for physiotherapists, it might be an under-appreciated aspect of physiotherapy practice.

Toby was the only participant who spoke favourably of a physiotherapy devised exercise plan: *'I've been doing that religiously for I would say 2 years everyday'*. There may be several reasons for Toby's adherence. Firstly, although it was challenging, Toby could do all the exercises independently. Furthermore, he recalled the physiotherapist offering him a choice of exercises (*'she said choose which you find to be of benefit to you'*) giving Toby a sense of control. Toby also swam three times a week and seemed to derive satisfaction from the routine and the sense of achievement;

*'I swim two miles a week, I go on three occasions because to do you know a mile, it would be too much for me. So the swimming and the physiotherapy, I know, even though it's hard, I don't see it as a chore [...] I enjoy going. [...] I thought well give myself some targets. [...] So last year I did 100 [miles] and this year I'm hoping to do 100, keep going as long as I can.'*

There is also a temporal reference in the above quotation; Toby was projecting into the future, hoping that he would be able to achieve the same distance as he did in the previous year. This sort of goal setting, similar to Julia's *'500 meters'*, *'140 stairs'*, perhaps provided a sense hope about the future, something positive and reassuringly repeatable, a sense of control amidst the uncertainty.

Toby believed that without the combination of swimming and physiotherapy (home exercises) he would have deteriorated more quickly: *'if you do physiotherapy, swimming, whatever, you can't stop the condition progressing but you can delay the progression'*. Also as noted above, Toby understood that exercise did not diminish the ataxia but toning up his leg muscles helped him feel more secure on his feet which engendered confidence and an improved sense of control over bodily impairment. Finally, with perhaps a veiled reference to an underlying low mood, he said: *'It's giving me a reason to get up in the morning'*. Toby emphasised the value he placed on having a sense of purpose and he derived benefit from the commitment to a particular routine, perhaps in similar ways to Julia's daily circuit of her residential complex.

However, Toby encountered the same difficulties as other participants with reference to inadequate reassessment and physiotherapists not fully understanding his condition (Table 10.2). It seemed that the majority of participants looked to physiotherapists as a resource for information and advice, but also to establish and maintain a sense of connection with an informed other. For most participants this sort of relationship and expertise seemed beyond the capacity of the physiotherapy services they encountered.

### **10.3.1 Summary**

In the previous subtheme it was suggested that exercise was not described by participants as simply a means of attending to the body. It was proposed that exercise, alongside other important and meaningful activities, perhaps helped to secure and preserve a sense of an integrated self; physically, psychologically and emotionally. Moreover, it was apparent that participants had worked out their own ways of managing the physical consequences of ataxia and had combined an attention to the body with an attention to other important aspects of their lives. By comparison, physiotherapists seemed, for the majority of participants, to be preoccupied with the body as a material thing. Exercise prescription, particularly home exercises, seemed to focus on the body as object, and at best only partially addressed the other important benefits of exercise described by the participants. As most participants were unable to persevere with exercise prescription without help, this type of physiotherapy seemed to reinforce failure and perpetuate disappointment. Furthermore, most participants described a sense of frustration with what appeared to be an inflexible commitment to traditional service models. For the majority, physiotherapy was viewed as a resource, a hoped-for source of expert information and advice that, in theory at least, could offer support in the struggle to manage life with ataxia. Direct encouragement from face-to-face

physiotherapy was also seen to offer a valued source of motivation that could keep them engaged with exercise. However, most participants seemed on the whole disappointed with what physiotherapy and physiotherapists offered in terms of their expertise in relation to ataxia, and their willingness to offer a long-term therapeutic alliance.

#### **10.4 Discussion**

Exercise, as described by participants in the present study, fulfilled multiple functions which seemed at odds, in most cases, with participants' accounts of their experience of physiotherapy. As discussed in the previous chapter, participants in the present study perceived living with ataxia as having the potential to disconnect them from others, to loosen the social threads that provided companionship and a sense of belonging. Being with others who shared similar concerns and experiences was felt to reduce or curtail disability-related distress. This chapter has shown that self-selected exercise helped to maintain authentic involvement with others and to preserve an integrated sense of self. Physiotherapy and prescribed home exercises, on the other hand, gave the condition and its symptoms, rather than the individual, more salience. Participants' accounts portrayed a lack of fit between their hopes for physiotherapy and their perception of what physiotherapists appeared to offer. Therefore the findings discussed here cautiously suggest that the meaning of self-chosen exercises and activities, and physiotherapy-prescribed exercises seemed on the whole rather different in these accounts. This disconnection might be considered as surprising new knowledge and is presented here for the first time with reference to the experiences of people living with progressive cerebellar ataxia.

A significant body of research suggests that exercise and other physical activity confers positive psychosocial effects on people living with a variety of long term conditions. For example, researchers who have explored the experience of dragon boat racing with breast cancer survivors (e.g. Tocher, 2002; Unruh and Elvin, 2004; Sabaston et al. 2007; McDonough et al. 2008) argued that training and competing in this sport had a wide range of therapeutic benefits including rebuilding self-confidence, regaining control over physical health and emotional well-being, as well as connecting with other women who had gone through similar experiences and who offered support. Similarly, physically and neurologically impaired participants in a qualitative study conducted by Carin-Levy and Jones (2006:10) described valuing their participation in scuba diving because it de-emphasised impairment and disability: *'I'm a human being and I'm equal to the people I dive with, when I go diving nobody knows [that I am] any different'*. This view reflected

Harry's account of hang-gliding. Others in the same study further emphasised the importance of undertaking an activity which also conferred social gains beyond diving itself. Participants described connecting with others through involvement in the "diving scene", a particular context where physical impairment was not an issue or topic of discussion or concern, and where identity as a diver took prominence. The importance of reciprocal connectedness also resonated with Julia's and Joan's accounts where social involvement seemed to safeguard their identity as a quilter or dancer. In these situations ataxia became less of a "master status" because social activity that was not focussed on ataxia deemphasised the impact of ataxia on the sense of self.

Carin-Levy and Jones (2006) also discussed the relevance of participating in scuba diving as a self-selected activity which, in addition to the benefits described above, offered an added sense of enjoyment and, through being appropriately challenging, a sense of achievement and satisfaction. Similar findings were reported by Mulligan et al. (2012). In this study, semi-structured interviews were conducted with 19 people with a variety of neurological conditions, including MS and Parkinson's disease. Those taking part in preferred activities described feeling empowered and fulfilled through engaging in the challenge of these activities and through this they described an intense feeling of satisfaction which became self-motivating. Parallels can be drawn with Scott's participation in water sports and Graham's team sport involvement, as well as Julia's home exercise programme, all self-chosen and offering considerable physical challenges but also importantly rewards (*'one star', 'it's a national league', '500 meters, 140 stairs'*) perhaps adding to the sense of achievement and satisfaction. Conversely, Mulligan et al. (2012) found that participants described prescribed exercise or exercise undertaken in an environment not of their preference or provided in a way that did not match their needs (e.g. a six week on, six week off rotation) as unfulfilling, unsatisfying and frustrating. This view resonates with some of the views of physiotherapy described by participants in the present study.

In the present study, physiotherapy seemed to be understood within a framework of the strict management of the symptoms of ataxia, and much less so within a context which preserved valued roles and activities. The present work also found that devising and maintaining exercise regimes entailed hard work and continued effort which was, at least in part, offset by the accomplishment of meaningful activities or other psychological and social benefits absent from most physiotherapy exercise programmes. However, even this understanding is not unproblematic. Toby, for example, strictly attended to impairment level exercises because he experienced these as offering him the sense of

control and routine that he valued. However, unlike Susan, he also participated in self-chosen activities such as swimming which he found enjoyable and challenging. For Toby, prescribed but individually selected exercises might have contributed to his sense of being an active person and not just a patient.

Rather than prioritising and engaging with a person's preferences and interests, the perceptions of the majority of participants in the present study would suggest perhaps that, in their experience, most physiotherapists held onto biomedical or reductionist views of the body, and in particular a view that exercise was constituted simply as repair or maintenance work for an impaired body. In turn, this way of thinking left little room to listen to or accommodate participants' perspectives or approaches to exercise, especially the particular and wide ranging benefits of exercise they experienced from their own self-directed activities. Nicholls and Gibson (2010) argued that physiotherapy should have long ago moved beyond the limits of a purely biomedically constructed understanding of the body. According to these authors, one of the reasons that physiotherapists might find this shift difficult was because their professional status has been, at least in part, predicated upon their expertise in defining normality from abnormality, a notion running entirely counter to a postmodern view of the body that, according to Nicholls and Gibson (2010:244), 'values diversity, inclusiveness and heterogeneous understandings of what constitutes "normal"'. The home exercise prescriptions described by the participants in the present study seemed, at least in part, to retain a biomedical view of the body which was perhaps in keeping with this very partial understanding of impairment.

In a situation where there is very limited evidence to guide physiotherapy practice (Marsden and Harris, 2011; Cassidy et al. 2009; Martin et al. 2009), a traditional, medicalised approach to exercise prescription, seemed, in the experience of the participants in the present study, to keep the impaired body away from others and perpetuated a dichotomised view of the body as either normal or abnormal (something that one participant even reflected by doing her physiotherapy stretches in private). This view failed to incorporate the participants' need to live a life of quality through maintaining social relationships, participating in valued activities and by countering depression whilst simultaneously coping with bodily impairment. Nicholls and Gibson (2010) argued that physiotherapists needed to develop a more imaginative and pluralistic practice which should be based on understanding the phenomenological dimensions of long term illness, and only by doing so would they develop a more inclusive understanding of the body and embodiment. The findings from the present

study support this view and extend it with particular reference to the lived experience of ataxia.

Adherence to physiotherapy exercise prescription was problematic for several participants in the present study and it is a well-recognised challenge in many areas of physiotherapy practice (Bassett, 2003). The issue is perhaps compounded in the case of ataxia by the lack of evidence available to guide practice, a source of frustration and concern for physiotherapists and patients alike (Cassidy et al. 2008). Even in situations where a home exercise programme has a sound evidence base, for example when regular home exercises will reduce pain, more than moderate adherence appears difficult to achieve (Thomas et al. 2002). Various strategies have been employed to improve adherence to physiotherapy home exercise programmes. Dean et al. (2005) described a phenomenological and demedicalised approach to improving adherence to exercise for low back pain that was founded on incorporating exercise into routine and habitual aspects of daily life; in much the same way as some of the participants in the present study managed exercise within, rather than separate from, the complexity of their own lives. Dean et al. (2005) was the first physiotherapist to look at adherence from a phenomenological perspective but more recent work has lent weight to the findings (see for example Medina-Mirapeix et al. 2009). Other authors have suggested instrumental as well psychosocial ways to improve adherence to exercise such as: providing exercise classes to supplement home based exercise (McCarthy et al. 2004), regular home visits every 3-4 weeks (McMurdo and Johnstone, 1995) or weekly visits for six weeks then telephone follow-up once a month (Ashburn et al. 2007). Taylor et al. (2004) used a more holistic approach that included the provision of an exercise log book, prescribing a small number of clearly described exercises for time efficient practice, developing personal autonomy, provision of information about exercise efficacy, working towards meaningful goals and developing the role of the physiotherapist as coach (monitoring and progressing exercises as well as providing emotional support and encouragement). None of the participants in the present study described any of these approaches to developing exercise adherence but they seemed to value the idea of the physiotherapist as coach; a person who could keep them motivated by face-to-face contact. The traditional method of providing six weeks of rehabilitation followed by the provision of a home exercise programme seemed to be the norm. Real world practice may not be able to mirror the kinds of support offered to patients within the context of the trials outlined above, however, there appears to be a body of evidence about effective exercise prescription that has not perhaps, as yet, been translated into practice.

Home exercises that only attend to bodily symptoms seemed to be narrowly conceived and inadequate in terms of conferring the benefits of exercise identified by the participants in the present study. In addition to the well-recognised links between exercise and psychological well-being for people living with mood related disorders (Scully et al. 1998; Lawlor and Hopker, 2001; Daley, 2008; Mead et al. 2009), work in other fields has also identified a consistent relationship between physical activity and improved quality of life for people living with other long term conditions. For example, Hurwitz et al. (2005) randomised 681 patients with low back pain into recreational physical activities or a back exercise programme. After 18 months the recreational group reported less back pain, less disability and less distress, whereas back exercises were associated with worse pain and disability. The researchers proposed that recreational activity was more effective partly because it alleviated depression. Motl et al. (2009) found that activity programmes for participants with multiple sclerosis might be associated with an improved quality of life if the activities were specifically directed towards minimising depression, fatigue or pain and maximising social support and self-efficacy. Moreover, the same authors suggested that efforts should focus on, amongst other things, 'enjoyable experiences' (Motl et al. 2009:119). Graham et al. (2008) found that a six month programme of seated group exercise for people with a range of long term conditions helped participants manage their mood, preserve and foster self-identity, and to connect with others in ways that limited illness-related psychological distress. Borkoles et al. (2008) explored the experience of exercise for a small group of people living with multiple sclerosis who were described as active exercisers. The findings emphasised the importance of retaining a sense of control over their condition even when it was uncertain whether exercise was having a direct (impairment level) effect, as well as retaining a valued sense of self and participating in enjoyable exercise-based activities with others.

The findings from the present study suggest that exercise can make a positive contribution to living with ataxia. This work has uncovered the ways in which exercise conferred multiple benefits that went beyond simple body maintenance. Physiotherapists were described as people who prescribed exercise but also as practitioners who could listen, empathise, encourage and provide practical advice and support. Unfortunately in the experience of the participants, it seemed that their physiotherapists were not always able or in a position to fulfil or sustain these roles, or to recognise and act on the level of expertise and resourcefulness participants had attained. Poorly managed partnership working and promotion of self-management strategies that are not underpinned by genuinely collaborative practices risk turning patients into 'agents managing their own

suffering' (Salmon and Young, 2005:228). Such practices may engender feelings of disempowerment and increased burden as reported by Susan but also Stella, Graham, Julia and Scott.

In accordance with the literature described above, the findings from this study suggest that the benefits of exercise should be understood in the broadest of possible terms. Genuine collaboration between physiotherapists and people living with ataxia, underpinned by a contextualised understanding of life with ataxia, would perhaps go some way towards developing physiotherapy practice and service delivery in ways that would be valued by people living with ataxia. This type of physiotherapy and exercise prescription would ideally foster autonomy, ownership and control, as well as the achievement of goals through doing enjoyable and meaningful activities. At the same time, advice and on-going support could be offered in a flexible and responsive manner. However, this may be difficult to achieve if the lack of evidence about effective interventions persists.

### **10.5 Conclusion**

This is the first study to explore experiential accounts about the role of exercise and physiotherapy for people living with ataxia. This super-ordinate theme emphasised the importance of understanding exercise and physiotherapy from a phenomenological perspective. Whilst the findings resonate with work that has explored this topic for people living with other long term conditions it has, at the same time, identified issues that would benefit from further research. These issues may not be particular to people living with ataxia but may mirror concerns identified by others. Nonetheless, these findings should perhaps provoke a re-evaluation of the ways in which physiotherapy is provided for people living with a progressive ataxia. Further research should also be undertaken which explores how physiotherapists conceptualise home exercise programmes and their role in working with people living with progressive neurological conditions.

## **Chapter 11**

### **Discussion**

#### **11.1 Introduction**

This study explored how people living with a progressive cerebellar ataxia made sense of this condition in the context of their everyday lives and how they perceived physiotherapy and physiotherapy services. A review of the literature identified that this type of enquiry had not been previously undertaken. Furthermore, there was little in the literature to help healthcare professionals to understand the particular issues that people living with progressive cerebellar ataxia faced in their day to day lives. The focus on physiotherapy and exercise was driven by discussions with colleagues and the researcher's experiences working with people living with long-term neurological conditions. The following research questions were formulated to address the topics outlined above:

1. What is the meaning of progressive cerebellar ataxia for people who live with this condition?
2. How do people living with a progressive cerebellar ataxia experience healthcare, and physiotherapy in particular?
3. What is the meaning of exercise and activity participation for people living with progressive cerebellar ataxia?

This chapter summarises the main themes derived from the analysis and offers a deeper analytic interpretation of the overall findings. It focuses on the findings that contribute new knowledge, as well as those that add to, or question, the comprehensiveness of existing theory. Thematic analysis, such as that undertaken with IPA may, by separating experiential accounts into parts or themes, fragment the lifeworld or dis-locate it in some way from lived experience (Joffe and Yardley, 2004). The following discussion therefore integrates the five super-ordinate themes presented and discussed in the previous five chapters (the parts) into an overarching theme, the gestalt (the whole). This approach illustrates the relationships between themes, and by doing so offers a higher level of abstraction and interpretation consistent with IPA (Smith et al. 2009). The intention is to bring the lifeworld to the fore without losing sight of the particular experiential narratives of individual participants. This chapter also reflects on the methods adopted to carry out this study, identifying its strengths and limitations, and offers a final reflexive overview.

## 11.2 Summary of the Main Findings

Each of the super-ordinate themes (summarised in Table 11.1) were discussed in the preceding chapters with reference to the literature in the field. This section offers a summary of the main findings before discussing the overarching theme of this study in-depth. As this study was the first to directly explore the subjective experience of progressive cerebellar ataxia, all the findings presented here are new.

**Table 11.1 Super-ordinate Themes**

Theme	Super-ordinate Theme	Description
1	<i>'I was like a pinball, I was bounced off this wall, went to that wall' (Toby)</i>	The embodied experience of living with progressive cerebellar ataxia
2	<i>'I don't want to seem handicapped in any way' (Stella)</i>	Identity, stigma and disrupted embodiment in public spaces and places
3	<i>'The cerebellum should be a tight cauliflower and mine was two sticks of celery' (Julia)</i>	Lifeworld meets biomedicine: a complex juxtaposition
4	<i>'Whenever it gives you a problem find a way round it, or fix it, you know.'</i> (Harry)	Wresting control in the face of uncertain and changing forces
5	<i>'It makes me feel better that I'm actually doing something' (Ted)</i>	Exercise: a multifaceted contributor to managing life with ataxia

Participants' accounts revealed novel and richly textured ways of understanding ataxia as an embodied phenomenon. Super-ordinate theme 1 illustrated that, for the majority of participants, their once comfortably familiar body had become disruptive to meaningful activities and projects. This was felt in more than just a physical sense. Participants described losing the easy and skilful interaction they had previously experienced between themselves and their world. Managing and accommodating a disordered body entailed novel ways of thinking about the body and thinking about space. As the body no longer buoyed the mind, cognitive resources were rapidly drained, further compromising participation in valued activities. Despite these changes, participants did not reject their body or understand it as something alien to the self. These findings are subtly different to those put forward by authors such as Zaner (1981), Toombs (1988, 1992) and Leder (1990) where alienation of the body in chronic illness is often foregrounded. These views are reviewed and discussed in more detail in the over-arching theme presented below. The findings summarised above do however, support calls put forward by authors writing from the perspective of disability studies that those wishing to understand the

subjective experience of chronic illness should not ignore the salience of physical impairment and the way it may shape the lives of disabled people (e.g. Crow, 1996; Thomas, 2007). At the same time, the findings from the present study also support those who have urged physiotherapists to look beyond their natural interest in the body as a physical entity (e.g. Marcum, 2004; Nicholls and Gibson, 2010). Only by moving beyond an understanding of the body as machine can it be possible to appreciate and effectively respond to the multiple ways in which impairment impacts on the experience of illness. This theme suggested that it is both possible and necessary to integrate an understanding of the lived body with an understanding of bodily impairment, in order to begin to comprehend the meaning of progressive cerebellar ataxia from the perspective of those who live with this condition.

Super-ordinate theme 2 cautiously pointed towards an understanding that progressive cerebellar ataxia involved a problematic disclosure of the self and “socially incompetent behaviours” that resonated with the findings of research with people living with Parkinson’s disease (Nijhof, 1995) and multiple sclerosis (Grytten and Måseide, 2006). Efforts to resist the negative consequences of stigma reduced participation in valued activities and were difficult to maintain in the midst of looming existential crises. These findings were similar to but did not perfectly resonate with Boutté’s (1987) ethnographic work about the experience of stigma for people living with Machado-Joseph disease (SCA3) in the Azores and the US. As discussed in chapter 7, the present study found that the forces that shaped each participant’s perceptions of stigma were not simply location- or culture-specific – or linked to general sociodemographic variables such as age or gender - but were person-specific. The majority of participants perceived that bodily disruption and incapacity invited critical scrutiny, but they made sense of these experiences and responded to them in highly situated ways. Goffman’s (1963) ideas about passing and covering remained valid, as did Scambler’s (1998) conceptualisation of felt stigma and internalised oppression. Most participants in the present study seemed to have unconsciously adopted the hegemony of socially constructed norms and customs. This is despite powerful and long-standing arguments made by those in disability studies about the inherent disablism underpinning perceptions about felt stigma and passing and covering behaviours (e.g. Thomas, 2010).

Participants described their local world as comprising inter-subjective spaces where their sense of self was almost permanently at stake. Under these circumstances, behavioural and cognitive approaches to managing stigma and identity were difficult to sustain. For example, Jim’s knowledge of the social model of disability offered

intellectual relief from the salience of stigma but this sort of “knowing” was difficult to enact and preserve in the face of lived experiences that undermined the value of these theoretical constructs. These findings suggest that those seeking to support people living with ataxia might need to understand that the meaning of stigma and the salience ascribed to it in these accounts was not stable. Not only did individuals differ in the way they perceived and interpreted stigma, the meaning of stigma varied within the same individual depending upon the particular contexts in which it was perceived, and how it interacted with the multiple meanings of living with this progressive condition. For example, for most participants stigma was highly salient in the public domain (e.g. at work, in the street and at social events) but for a few participants, discrediting experiences in the home, effected by family members, appeared more salient and hurtful than those believed to be enacted by strangers. For others, physical decline uncovered hegemonic beliefs about the value of independent walking that challenged the sense of self and threatened to reduce participation in meaningful activities.

Super-ordinate theme 3 extended the findings of Daker-White et al. (2011) by emphasising the arduous and uncertain process of diagnosis described in most accounts. Participants in the present study struggled to develop meaningful partnerships with healthcare professionals and they perceived, on the whole, an unbreachable gap between what they were looking for and what was offered. It seemed important, for example, to understand that living with ataxia was not simply a physical disorder but also involved on-going adjustment to change and existential turmoil that was rarely, if ever, addressed. Comparable experiences have also been reported by people living with FRA (White et al. 2010). In the present study, a strong sense of chronic uncertainty also emerged from the analysis of participants’ accounts. This stemmed from the provisional nature of most diagnoses of progressive cerebellar ataxia which meant that there was always something unknowable about living with this condition. Tied to this uncertainty was a persistent but ambiguous undercurrent about the inheritable nature of ataxia and the burden of responsibility for future generations. The lived experience of cerebellar ataxia differed in this sense from the kinds of psychological issues that face people living with known inheritable conditions such as Huntington’s disease where there is more certainty about both the pattern of inheritance and the illness trajectory (Smith et al. 2002). Because participants seemed quite cautious when speaking about living with a potentially inheritable condition, further research which prioritises this topic is required. The findings of such work may further inform the practice of genetic counselling. With reference to Chapman and Smith (2002), IPA would seem well placed to explore these issues in more depth.

Running through the accounts, and as described and discussed in super-ordinate theme 4, was a sense that participants were engaged in a constant process of adjusting to the vagaries of life with ataxia, whilst at the same time safeguarding valued roles and relationships. Others living with ataxia or other long-term conditions were perceived as a reference point, a valued source of intelligence when participants' lives seemed for the most part unintelligible and in flux. The adoption of a certain stance or philosophy towards living with ataxia was identified in the majority of accounts. These perspectives were particular to each participant, but were directed towards maintaining a positive focus by reducing the salience of ataxia, and by focusing on activities, roles and relationships that conferred a sense of satisfaction, continuity and purpose. These activities were often tempered by living with a heightened sense of time and a loss of spontaneity. This way of living with ataxia was by no means straightforward. Participants emphasised the hardship, setbacks and on-going effort required to sustain a positive outlook and acknowledged the pain involved in accepting temporary or permanent loss of significant and meaningful features of their lives. This new work deepened the understanding of biographical disruption first advanced by Bury (1982), as well as G Williams' (1984) conception of narrative reconstruction. It also added to newer work that introduced the concept of co-existing biographies where, in chronic illness, a familiar biography may be intertwined with a disrupted biography (Reynolds and Prior, 2003; Reeve et al. 2010). In these studies, people living with long-term conditions were found to manage the complex co-existence of positive and negative strands of their lives with difficulty. The present study emphasised the highly contextualised and fragile ways in which individuals living with progressive cerebellar ataxia also attempted to manage this complex interweaving, and to fashion a sense of control over their lives in the face of chronic uncertainty.

Super-ordinate theme 5 emphasised the importance of understanding exercise and physiotherapy from a phenomenological perspective. The meaning of exercise, as described by participants in this study, stretched beyond a concern with the physical body to psychosocial domains and, by doing so, helped to secure and preserve an integrated sense of self. These findings supported the views of others (Tocher et al. 2002; Carin-Levy and Jones, 2006; Borkoles et al. 2008) who suggested that, for people living with long-term health conditions, exercise, even if it conferred no direct impairment-level effects, offered multiple benefits. These included enhancing the sense of self, whilst also reducing the salience of a patient-focussed identity. Furthermore, participants in the present study derived satisfaction from participating in self-selected exercise. Mulligan et al. (2012) reported similar findings. These authors found that

people living with progressive neurological conditions who participated in preferred activities experienced these as more fulfilling and empowering than exercise that did not match their preferences in terms of type or location. The present study also found that physiotherapy was seen as having a rather rigid focus on the impaired body, and as failing to acknowledge the value of exercise in terms of preserving valued relationships, sustaining meaningful activities and combatting issues such as depression and stigma. Physiotherapists were also viewed as being unable to, or not in a position to, appreciate the importance placed on their potential role as coach, and as unable to provide the face to face contact valued by participants in this study. In line with arguments made by Nicholls and Gibson (2010), the findings from this work cautiously suggest that physiotherapists may need to develop a more three-dimensional approach towards understanding and working with people living with progressive cerebellar ataxia. This approach would incorporate not only an understanding of the impaired body, but also a more pluralistic view that accommodates the psychosocial meaning of exercise and which respects the value participants placed on collaborative working.

Whilst common themes were identified across the corpus of data, the detailed description and discussion of individual accounts exposed and emphasised individual variety about how progressive cerebellar ataxia was experienced and accommodated. This approach also worked to highlight differences in the way participants attempted to preserve and sustain meaning and value in their lives. The following discussion of the over-arching theme pulls the super-ordinate themes together, but retains the idiographic approach by setting out evidence from across the corpus to support the developing argument.

### **11.3 Over-arching Theme: *'Can't do it no more. And then that sort of thing it's like bites a bit, but ...you evolve, you evolve to suit where you're at'* (Harry)**

**Description: Retaining a homelike way of being-in-the-world**

#### **11.3.1 Illness as an Unhomelike Way of Being-in-the-World**

The findings from this study are interrogated here with reference firstly to Svenaeus' (2000a, b, 2001, 2011) phenomenological theory of illness as unhomelike being-in-the-world, and, secondly, Todres' and Galvin's (2010) existential theory of well-being. As these theories were elaborated in the literature relatively recently, an overview of each theory is introduced in Appendix M. In responding to Svenaeus' call for his interpretation of Heidegger and his conception of illness to be challenged by empirical evidence, the

following section demonstrates how the present study both supports Svenaeus' (2000a, b, 2001, 2011) view regarding the unhomelike experience of illness, but questions the contention that illness is always experienced as some sort of alienation. It is argued that by looking for typicality, Svenaeus has necessarily overlooked the nuance and texture of different illness experiences that might refine his general phenomenology of the experience of illness.

It is suggested here firstly, that the experience of living with progressive cerebellar ataxia, as recounted by participants in this study, is close to Heidegger's original meaning of unhomelike: an indefinite or uncertain, strange or disturbing being-in-the-world. It is here where the findings from this study add empirical weight to Svenaeus' (2000a, b, 2001, 2011) contention that illness may be experienced as an unhomelike being-in-the-world (discussed below). Secondly, this disturbance was not necessarily or always experienced in terms of bodily or temporal alienation. As argued in chapter 6 (The Embodied Experience of Living with Progressive Cerebellar Ataxia), ill health that manifests itself abruptly and unpredictably and/or which wreaks sudden, distressing or humiliating experiences (e.g. Svenaeus' examples of chronic pain and stroke, and Toombs' (1992) phenomenological account of living with MS) may alienate the person contending with these devastations *from* their body. In these instances it is possible to see that the body may be experienced as having been invaded by some sort of alien and malevolent force. Chapter 6 also presented further instances from the literature where the body had or could be understood as alien to the self, for example, following a complete loss of bodily control, or when the body seems to take on a life of its own (e.g. as described by Sacks, 1985; Finlay, 2003b; Gallagher, 2005). In these cases, the etymological meaning of alien as other than the self or belonging to someone else (Shorter Oxford English Dictionary, 2002) would seem to capture the unhomelikeness of this experience and lend weight to Svenaeus' arguments that in illness the body is experienced as alien. However, this was not always the case in what was understood of the lived experience of progressive cerebellar ataxia where a more ambiguous experience of the body unfolded. It is here, in the midst of this ambiguity, where the present study qualifies Svenaeus' (2000a, b; 2001, 2011) arguments. Participants described their early experiences of ataxia as strange, disturbing and unfathomable but not necessarily alien. This quotation from Toby's account conveyed this most clearly;

*'... from the canteen back to our production facility they used to have a corridor about 50 feet long. [...] which would be the width of a door, 3 foot, whatever. And I could not ... particularly if people were behind me, walking behind me, that tends to make me worse*

*... but I was like a pinball, I was bounced off this wall, went to that wall, I could not walk in a straight line down that corridor [...] Really strange.'*

As discussed in chapter 6, this quotation seemed to communicate a loss of control. It was argued that Toby seemed to retain a sense of ownership of his body, the repeated use of the first person 'I' emphasises this point. At the same time, it seemed that his sense of agency was also disrupted. This was pointed out as an important aspect to understanding the lived experience of ataxia. However, it was also where the ambiguity came to the fore. It is possible to interpret this extract as meaning that Toby felt as if his body had emerged as an "it-ness", an alien thing separate from the self. However, this interpretation overlooks the context of the extract presented above. With reference to Morris (2008b:403), the corridor at work no longer appeared to Toby as a 'meaningful space of choice' (*'I could not walk in a straight line down that corridor'*) and as such Toby experienced a reduction in the situated possibility of his being-in-the-world. *'I was like a pinball'* communicates not simply a loss of agency but a more profound uncoupling from the world as the ground or foundation for possible action (walking down the corridor to get back to work). Disrupted walking, in this sense, curtailed Toby's freedom to spontaneously respond to a particular spatial situation and in this sense it could be said that Toby experienced an inhospitable or unhomelike being-in-the-world but not necessarily an alienating experience.

As described by Toby and others (see chapter 6), in ataxia it seemed that the mutual dependence or empathy between self and world broke down as the ability to pre-cognitively anticipate and incorporate the environment in action failed. As a result, the world became observed in a newly conscious way; kerbs, corridors, doors, walls and passers-by held the attention and effort was expended in trying to maintain equilibrium. The physical environment emerged as something to contend with and thought-fully navigate in a way that contrasted with previous experience. It is therefore argued here that living with progressive cerebellar ataxia, as recounted by participants in this study, involved a disruption of skilful *situated* coping. Further examples were provided in chapter 6 where the body was experienced as strange and unpredictable, not simply as a corporeal thing but also in the sense of it being disruptive to projects and activities. This study revealed that it is the loss of the optimal bodily attitudes that normally provide the grip on the world, and from which experience is integrated and secured (Carman, 2008), that seems particular to life with ataxia. It is here that Merleau-Ponty's conceptualisation of human embodiment lends further insight.

According to Merleau-Ponty (2002 [1945]:87), human embodiment can only be understood:

‘by abandoning the body as object, *partes extra partes*, and by going back to the body that I experience at this moment [...] I cannot understand the function of the living body except by enacting it myself, and except in so far as I am a body which rises towards the world.’

Here, Merleau-Ponty not only rejects the view of the body as object but also, by saying ‘I am a body’, he intentionally blurs the distinction between the subjective ‘I’ and the body as lived and involved in the world (Morris, 2008a). In this sense then, and for Merleau-Ponty in particular, the ‘I’ and the lived body are synonymous: the body is no mere appendage of a separate thinking consciousness. This mind-body merger is underpinned by two key concepts, the body schema and habit. Under normal circumstances, our bodies are optimally orientated via the ‘body schema’ to maintain the right kind of bodily postures, attitudes and actions that are required for our practical engagement in the world (Merleau-Ponty, 2002 [1945]:113). The body schema therefore refers to the pre-theoretical ability to engage in projects and tasks without the need for conscious attention or close monitoring of the body (Gallagher, 2005). For Merleau-Ponty ‘It is the body that ‘understands’ in the acquisition of habit [...] To understand is to experience the harmony between what we aim for and what is given, between intention and performance’ (2002 [1945]:167). So “habit” refers to a kind of bodily intelligence that enables us to skilfully cope with the things we do in particular environments without cognitive effort (Reynolds, 2005).

Habit then, is neither a form of knowledge understood as facts or data, something that can be articulated or rendered explicit, and nor is it an involuntary or reflex action. Rather it is body-knowledge, held in the body and ‘forthcoming only when bodily effort is made, and cannot be formulated in detachment from that effort’ (Merleau-Ponty, 2002 [1945]:166). For Merleau-Ponty ‘habit has its abode neither in thought nor in the objective body’ but in the lived body in the world (2002 [1945]:167). Removing the body from the world or trying to explicate movement by putting it into words or thoughts will only ever achieve an approximation of what is normally achieved via habit and the body schema.

Furthermore, for Merleau-Ponty, the world is a situation that is actively inhabited or taken up through the body;

'The body is the vehicle of being in the world, and having a body is, for a living creature, to be *intervolved* in a definite environment, to identify oneself with certain projects and to be continually committed to them.'  
(Merleau-Ponty, 2002 [1945]:94, added emphasis)

It is the interpenetration that is important here, the winding together of body-projects-world. In other words, human momentum (our tasks, projects, cares and concerns) propels us into a world; this world is taken up by us and incorporated through our intentional activity. So, in our natural way of being, not only is there a blurring of the distinction between mind and body but the distinction between the body and the environment is also blurred (Merleau-Ponty, 2002 [1945]; Gallagher, 1986). The intertwining of body and world is a two way process; there is an empathy between the lived environment and the body. The body integrates itself with the environment, adapting to particular conditions and circumstances. In a sense, the environment regulates the body; it calls for a particular bodily style, and in response to this call, by adopting a posture or by moving in a particular way, by working *with* the environment, the body becomes the expression of the environment. In other words the body and the environment 'approach unity' (Gallagher, 1986:163).

The mind then is not separate from the body and nor is the body thoughtfully imposed on the world (Gallagher, 1986). In normal functioning, the body is open to and accommodates opportunities and situations as they present themselves within the world in a spontaneous (un-thinking like) way. When the body schema fails, as in illness (and, as argued here, in ataxia), Merleau-Ponty suggests that the natural equilibrium or rapport between body and environment is, 'thrown out of gear' or 'off the rails' (2002 [1945]:133, 134). This disequilibrium, the disruption of habit, changes our way of being in the world because the body can no longer respond to the "call" of a particular situation or context. Rather than being at the periphery of our experience, the body emerges from its 'mute and shadowy existence [...] announcing itself as painful, fatigued, distorted, clumsy' (Gallagher, 1986:152). At the same time the rapport or shared logic between the body and the environment is disturbed (Merleau-Ponty 2002 [1945]; Gallagher, 1986). As recounted by participants in this study, the environment materialises as space to be reckoned with and negotiated. It is exactly Merleau-Ponty's sense of disrupted equilibrium, this particular sense of embodied unhomelikeness, rather than alienation per se that seems to be evident in the lived experience of cerebellar ataxia as recounted by participants in this study. Table 11.2 offers further examples from participants' accounts of experiences that could be considered as an unhomelike (but not necessarily alien) being-in-the-world. These have been divided into separate dimensions of the

lifeworld as suggested by Svenaeus (2000b, 2011), with his reference to unhomelike embodiment and alienation (discussed above), and unhomelike temporality and alienation. However, this categorisation has been expanded to include other aspects of the lifeworld as suggested by Todres and Galvin (2010).

**Table 11.2 Ataxia as an Unhomelike Being-in-the-world**

Lifeworld Dimension	Participant Quotation (page and line number)	Interpretation
Spatial unhomelikeness	<i>Graham: 'sometimes I do give in and think I don't want to walk back, so I don't go out [...] you start turning things down because you know that's outside your comfort zone' (6:25)</i>	Loss of the freedom to experience a spatial situation as a possibility, a closing down of choices.
Mooded unhomelikeness	<i>Joan: 'I don't like not to be busy. Some people are people who can relax but I'm not. [...] So it's a continuous battle to make myself relax. The future's a bit scary and I know I've got to get to grips with relaxing' (10:5)</i>	Thoughts of the future provoke anxiety, Joan struggles to accept the changes wrought by ataxia, and, not always succeeding, she flees from the inevitability of what she sees coming towards her.
Intersubjective unhomelikeness	<i>Julia: 'he [my son] would go and get me things but he reckons it's best if I come ... but whenever we cross the road he always holds me by the scruff of the collar [...] I say to him 'Have you any idea how that makes me feel?' (11:18)</i>	Disruption of kinship and togetherness, mother and son are no longer in tune.
Temporal unhomelikeness	<i>Susan: 'it shortens the time that you have. All the things you used to be able to do in an hour or a day, everything takes so much longer, so you don't have so much time' (6:27)</i>	Susan is a hostage of time, there is no time to play with.

Separating aspects of lifeworld from each other in this way helps to demonstrate how cerebellar ataxia could be understood as an experience of unhomelike being-in-the-world, but it also disrupts the ways in which the lifeworld is experienced as a unified whole. For example, “mooded unhomelikeness” in Table 11.2 could also suggest an unhomelike sense of identity or personhood (Ashworth, 2003). As discussed in chapter 9 (Wresting Control in the Face of Uncertain and Changing Forces), what emerges in Joan’s account is not simply her anxiety about the future but the ways in which she feels that her sense of identity is under threat. She foresees her usual active being-in-the-world as coming to an end. Joan struggles to accept these changes (*‘continuous battle’*) and feels perhaps that she has to become someone else (a person who relaxes) in order to cope with what is ahead of her.

Returning to the super-ordinate themes presented in Table 11.1 (pp. 241) and with reference to Table 11.2 (above), and the preceding discussion of the findings, it is argued here that participants' experiential accounts lend support to Svenaeus' (2000a, b, 2001, 2011) theory of illness as an unhomelike being-in-the-world. Evidence for this proposal can be found in each of the superordinate themes presented and discussed in chapters 6-10, with particular reference to disrupted embodiment and spatiality (emphasised in theme 1 but also in theme 5 where unwelcome salience is placed on the impaired body), intersubjectivity (emphasised in theme 2 and 3 in connection with identity, stigma and biomedicine, and also theme 5 with reference to interactions and relationship with physiotherapists) and temporality (theme 4, where participants reported living with a heightened awareness of time as slipping away or pressing in on their activities and projects). This view reflects the experience of participants in their ordinary lived experience as well as their particular experience of healthcare and physiotherapy (theme 3 and 5). It is further argued that participants' accounts not only resonate with some of Svenaeus' claims and add new empirical weight, but also question part of his theory: the inevitability of illness as experienced as an alienation from the self and the world. The arguments put forward here qualify the generalizability of this part of his theory with reference to the lived experience of cerebellar ataxia. These arguments are new and, as yet, have not been addressed in the literature.

Todres and Galvin (2010) suggested that the unhomelike quality of illness experience could be overcome by promoting well-being. This view, that in illness it is possible to recover a sense of homelike being-in-the-world, was also advanced in a theoretical but not fully elaborated form by Svenaeus (2000a, b, 2001, 2011). The discussion that follows shows how participants in the present study both felt and resisted unhomelike being-in-the-world, and, through their efforts to regain and sustain a life worth living, they attempted to 'evo/ve' or progress towards a more homelike existence.

### **11.3.2 The Possibility of Homecoming: An Existential Theory of Well-being**

In their interpretation of Heidegger's later philosophy, Todres and Galvin (2010:3) proposed that 'homelessness gives mobility to life as a positive potential, while homecoming gives peace to life as a positive potential'. According to this theory, existential homelessness, as experienced in illness, may firstly launch possibilities for 'existential mobility'. Rather than presenting a somewhat nihilistic position whereby the meaningless of existence has to be faced with a sort of empty stoicism, homelessness may be reframed within a more positive outlook. Todres and Galvin (2010:3) argued that

homelessness opens up a 'creative restlessness', a 'calling to future possibilities' 'an energising potential' or a 'sense of adventure' which motivates the pursuit of homecoming. This sort of homecoming does not seek refuge in what was there before (it is not a going-back-to; illness and suffering are not taken away) but opens up or re-connects with possible horizons of experience. Mobility therefore should be understood as offering possibility and flow. The concepts of post-traumatic growth (Tedeschi and Calhoun, 2004) and transformational coping (Kobasa, 1979; Maddi, 2006) are certainly related to the ideas put forward here. However, Todres and Galvin (2010) frame their theory of existential homecoming within phenomenological rather than cognitive constructs. The practical application of this theory therefore rests on looking for opportunities to experience homecoming within fundamental lifeworld structures such as temporality, intersubjectivity, embodiment, spatiality and mood. Galvin and Todres (2011) identified the experiential domains within which well-being could be emphasised in a literal or existential sense, as spatial mobility, temporal mobility, intersubjective mobility, and so on.

Secondly, existential homelessness, as experienced in illness, may similarly launch possibilities for 'existential dwelling' (Todres and Galvin, 2010:4). Described as a 'letting-be-ness', this sort of dwelling is not just a psychological state but a coming home to "what is". In this sense, ill health and all that it entails, is accommodated. Making room for whatever "is there" is thought to constitute a form of peace. Dwelling is therefore best considered as 'an acceptance of things as they are' (op. cit.), rather than a form of resolute courage or fortitude. Dwelling emphasises rootedness, staying connected to people and experiences that hold meaning and preserving a sense of continuity. In this sense dwelling might be considered the opposite of Angst; it puts a check on anguish and torment that might otherwise be overwhelming. For Galvin and Todres (2011), well-being may be realised through emphasising possibilities for existential dwelling via the experiential domains of the lifeworld such as spatial dwelling, temporal dwelling, intersubjective dwelling, and so on.

The deepest possibility for well-being, according to Todres and Galvin (2010), occurs when dwelling and mobility come together. Bringing these terms together may seem paradoxical, but for these authors the intertwining of mobility (understood as possibility and flow) and dwelling (understood as peace and rootedness) encompass well-being. 'Dwelling-mobility' embraces both a call towards possibilities, as well as acceptance of what has been given (Todres and Galvin, 2010:5). This capacity for both dwelling and mobility remains grounded in the lifeworld i.e. well-being can be realised through spatial

dwelling-mobility, temporal dwelling-mobility, intersubjective dwelling-mobility and so on. Although these structures of the lifeworld are interrelated, Galvin and Todres (2011) argued that it is possible in healthcare practice to consider each component as a means of identifying different well-being possibilities.

Todres and Galvin (2010:5) provided the following explanation, 'when dwelling is experienced in a temporal way, there is a sense of being grounded in the present moment, when mobility is experienced in a temporal way there is a feeling of flow'. The deepest possibility of well-being experienced through temporality is temporal dwelling-mobility. Here the future is viewed as welcoming whilst the present is enjoyed in the moment. Todres and Galvin (2010) further argued that individuals have a tacit sense of dwelling-mobility and find their own ways of moving towards well-being. It is argued here, with reference to the experiential accounts of participants in the present study that living with a progressive cerebellar ataxia entailed a sense of homelessness which co-existed with a journey towards homecoming i.e. the possibilities for well-being *co-evolved* with suffering and the vicissitudes of life with ataxia. For example, participants spoke about their existential discomfort in terms of their uncertainty about the future, as well as their embodied discomfort, social discomfort, disordered movement and overwhelming fatigue. At the same time, participants recounted how they continued to participate in valued activities and relationships with others which conveyed a sense of moving forward, as well as a settling of existential angst, albeit temporarily. Similar findings were identified by Reynolds and Prior (2003) where women living with MS acknowledged the complex coexistence of positive and negative life experiences as an interweaving of sparkling and darker threads in the tapestry of their lives. However, this is the first time that this similarly nuanced understanding of life with ataxia has been presented. Furthermore, for the most part, participants in the present study found their own ways of working towards homecoming, often in spite of their healthcare experiences (as discussed in super-ordinate themes 3, biomedicine, and 5, exercise and physiotherapy). The following examples from the present study are used to illustrate how the findings from this study may add experiential weight to Todres and Galvin's (2010) theory of existential well-being. Not all the possible permutations are presented here (i.e. not all lifeworld structures are combined with mobility and dwelling) as they did not all occur in participants' accounts. The well-being dimensions used in these examples are taken from Galvin and Todres (2011:3-12). Several examples from Bill's account are used to build a clearer picture about how these concepts might be used to help understand the particular experiences of one individual. Examples from other participants are also included.

### **Embodied Dwelling: comfort**

Embodied-dwelling is a well-being experience described by Galvin and Todres (2011) as a pre-reflective sense of bodily comfort, a body that is simply present, unannounced, reliably doing what needs to be done. As discussed in super-ordinate theme 1, Bill described living with ataxia as *'awkward, ungainly and painful'*. It was suggested that he had lost the sense of his comfortably familiar, taken-for-granted body and it is argued here that this could be further interpreted as an experience of unhomelike embodiment. Later in his account Bill described the way in which massage seemed to help sustain a bodily sense of well-being:

*'I've got a good experience of massage, and I tend to have a very positive reaction to that [...] I go every few weeks for a shoulder massage [...] it works very effectively, particularly my right shoulder which is very important because that's the hand you hold the most in.'*

Galvin and Todres (2011) argued that attending to a person's sense of bodily comfort may attenuate a preoccupation with the body in the sense that something is, or could go, "wrong". In the quotation above, Bill seemed particularly concerned about his right shoulder. So, through massage Bill may have found some relief from his bodily pain but also a sense of existential settling, putting to rest, at least temporarily, concerns about what might happen if he is no longer able to use his right hand. Massage could also be understood in this context as an active strategy for delaying this frightening possibility. Attending to Bill's right shoulder in this way addresses his existential discomfort, but may not confer any measurable impairment level benefit. This may be problematic for a healthcare system where outcomes are measured along biomedical lines.

### **Embodied Mobility: vitality**

Embodied mobility is a well-being experience that emphasises the body as full of vitality and energy. It accentuates a feeling of bodily capacity and "can do" (Galvin and Todres, 2011). Much of the time Scott experienced his body as short of energy. He described feeling depleted, exhausted and lacking functional competence. For example, he found mealtimes sometimes very difficult: *'You stagger over, you get what you can, cook it up, get it down your neck and you go and lie down and you think 'Ugh, I'm dying''*. However, there were times, when he went to the gym, where he experienced a sense of bodily vitality:

*Scott: '[I] feel an awful lot better just by having a strong work out, kind of like a cleaning effect, all the blood rushing to your brain ... not quite sure how to put it.'*

Exercising at the gym opened up possibilities for experiencing his body in a way that he valued and perhaps needed, but as with Bill it did not necessarily confer any impairment level effects. Embodied mobility constitutes a kind of well-being for Scott because he seemed to experience his body in a positive way (*'I feel an awful lot better', 'cleaning effect'*) and it may have liberated him, at least temporarily and in an existential sense, from a body that he felt put limits on his possibilities as well as, perhaps, his pleasures.

### **Identity Mobility: 'I can'**

Identity mobility is a well-being experience that emphasises the sense of 'being able to' (Galvin and Todres, 2011:8). It describes a heightened feeling of personal agency and confidence in the future achievement of personally meaningful goals. In the following quotation Harry seems to capture the idea that well-being can be realised through moving towards future possibilities that are consistent with his personal goals:

*Harry: I've always wanted a bike, fit in with the guys [...] it's only in the past couple of years they've started legalising quads, four wheeled motor bikes [...] and we were like ... went out and started harassing people to ... how do we get one?'*

At an existential level, Harry experiences himself as 'being on the move' (Galvin and Todres, 2011:8). There is the feeling here that he has capacities and potentials that are yet to be realised, and this provides a sense of 'ontological security' and ontological mobility (Galvin and Todres, 2011:9). Harry is unfinished, there is more to be done, his identity is still in the making and this contributes to his sense of well-being. Thinking and acting in terms of an "I can" (*'how do we get one?'*) perhaps preserves a sense of "being able to" and for Harry, this may help him give less salience to a disabled identity that carries an unwelcome sense of permanence and stasis. Also, the male camaraderie connected to the achievement of this goal perhaps also speaks for Harry's sense of "I can". He is part of a group of male friends who want to do the same thing, who are moving forward in the same direction, he is a would-be biker and so are his friends.

Joan spoke in similar terms. She used an electric scooter or buggy for long distances outside but found it difficult to lift in and out of the car. However, she had a plan which she thought would maintain her independence and mobility:

*'if I got a car that was fairly tall at the back, I could have a hoist to put the buggy in, then I would really get back to being independent again from that point of view.'*

Here Joan can be seen as making plans for her future possibilities, for moving forward in a positive way that may work to enhance her belief in herself as an independent person, an "I can".

### **Identity Dwelling: 'I am'**

In contrast to Harry's account above, Bill seemed to suggest that he might have derived some sense of well-being from accepting "what is". Identity dwelling refers to a feeling that a person is continuous with their sense of self, supported by uninterrupted contexts that confirm the sense of identity (Galvin and Todres, 2011). As discussed in chapter 9, Bill seemed to be reconciled to his life as it was lived with a sense of patient fortitude: *'You get used to it, get to the end of the week, you feel 'that's one more down'. So we survive, we've got by'*. Here, Bill seemed to feel some degree of "belonging-with" in the sense that his life remained connected and continuous with his relationship with his wife. However, as discussed previously, beneath what seemed to be, at first glance, an untroubled sense of dwelling, ran an undercurrent of existential concern regarding the enduring nature of his marriage. Therefore Bill's well-being, as defined by the continuity of his most meaningful relationships, his sense of dwelling, 'I am', was perhaps not fully realised.

### **Temporal Mobility: future orientation**

Temporal mobility is a well-being experience that emphasises future possibilities and provides a sense of purpose to activities and projects (Galvin and Todres, 2011). Toby swam regularly. He believed this activity may have helped to maintain his muscle strength, but also understood that it probably made little if any difference to the underlying ataxia. However, by adding a challenge and future target, it is possible to see how swimming contributed to Toby's sense of well-being:

*Toby: 'I thought, well, give myself some targets [...] So last year I [swam] 100 [miles] and this year I'm hoping to do 100, keep going for as long as I can.'*

Swimming orientated Toby towards the future in a positive way through progressing a valued project or task. In this sense, for Toby, the future invites possibility and promotes existential well-being. This perhaps hidden benefit seemed to elude Toby's neurologist who possibly viewed swimming from a purely biomedical perspective. Toby explained

that having told him about swimming, it appeared to Toby that the consultant rather dismissed it: *'the neurologist said it won't particularly do me any good.'*

### **Spatial Mobility: adventurous horizons**

Spatial mobility is a well-being experience that stresses the value of literal or metaphorical movement, of 'being on the road', open to new adventures (Galvin and Todres, 2011:3). Bill was unable to leave his home without assistance and in this sense he had limited opportunities to experience "being on the move", the actual exploration of new and interesting places. However, Bill had retained a metaphorical sense of spatial mobility. Bill's wife went for walks with a local volunteer and took photographs as they walked along:

*'Mary takes [the pictures] with a digital camera and puts them on the computer and we look at them. [...] having looked at the pictures, we then look at where she's been on the internet. But [until then] the route's a mystery because the man that she walks with changes his mind on the way.'*

In this sense Bill retained the possibility of experiencing adventurous horizons, and this may have contributed to an overall sense of well-being both through these direct experiences, but also by reducing a sense of spatial unhomelikeness in which his possibilities for movement and adventure were severely restricted.

### **Intersubjective Dwelling: kinship and belonging**

Whilst the previous example may also offer experiential evidence of intersubjective dwelling with regards to kinship (e.g. Bill may have perceived a feeling of well-being and "at homeness" through the companionship offered in undertaking this virtual journey with his wife), Bill also sought a sense of belonging from similar others. Intersubjective dwelling emphasises well-being achieved by a sense of being at home with others. It describes a "meeting of minds", a compatibility with others that fosters a sense of familiar and comforting 'inter-personal connection' (Galvin and Todres, 2011:6). As discussed in super-ordinate theme 4, Bill seemed to find consolation from listening to a regular online broadcast about people living with disability:

Bill: *'Like a real club, it has its own language and kind of knowing glances, whatever, that you belong to it and you can get some kind of comfort from it. [...] In terms of you're not the only one.'*

The reference to '*knowing glances*' and '*own language*' emphasised the importance of seeking others living through similar difficulties who offered a sense of at homeness or belonging not apparent in other relationships, a sense of inter-subjective dwelling with what had been given.

These examples offered a further interpretation of participants' accounts which extended the findings presented in previous chapters. This further interpretation lends weight to Todres' and Galvin's (2010) theory of existential well-being by showing the ways in which participants' lived experience included aspects of homelike embodied dwelling, embodied mobility, identity mobility, identity dwelling, spatial mobility, temporal mobility and intersubjective dwelling. However, as noted above, possibilities for well-being *co-evolved* with suffering and the vicissitudes of life with ataxia. The following example from Bill's account serves as a reminder that for participants in this study, the possibility for existential homecoming was always experienced as part and parcel of unhomelike being-in-the-world.

*Bill: 'I think it's kind of ... the walls are moving in as it were. [...] I tend to have a low level routine as it were, that each day is fairly similar to the other, except for minor things like Wednesday is bin day, Tuesday is the breadman coming. That kind of ... neither of which affect me in one sense because I don't put the bin down and I don't go out to the bread van. Because you know people say 'what's Tuesday?' I think – breadman. That's what marks it from being different to other days as it were.'*

In terms of existential well-being, it appears here that Bill lacked a sense of temporal mobility. He described a deadening routine, a keenly felt closing down of possibilities (*'the walls are moving in'*). He was aware of events that marked out one day from another but he felt disconnected from them (*'neither of which affect me'*). Bill did not seem to derive a sense of comfort from the weekly routine or the passing of time, only a lack of forward momentum and the shrinking of possibilities. Taking the examples from Bill's account as a whole it is possible to see how life with ataxia could involve both painful unhomelike experiences and opportunities for improving well-being through exploiting avenues for homelike being-in-the-world. Similar but deeply contextualised findings were present in the majority of accounts.

### 11.3.3 Retaining a Homelike Way of Being-in-the-world: the Lived Experience of Progressive Cerebellar Ataxia

In summary, the findings from this study cautiously suggest that participants portrayed living with progressive cerebellar ataxia as an unhomelike way of being-in-the-world that affected all aspects of their lifeworld. Critically, in the midst of these strange and unwelcome disruptions, participants also found ways to secure homelike ways of being-in-the-world through sustaining meaningful and valued activities and relationships. This co-existence of negative and positive experiences was found in all cases, and was perhaps best captured by Harry: *'Can't do it no more. And then that sort of thing it's like bites a bit, but ...you evolve, you evolve to suit where you're at'*. As discussed previously, Harry, like the majority of participants in this study, acknowledged the hurt involved in living with ataxia but he continued to move forward or to evolve (in terms of embodiment, temporality, intersubjectivity and spatiality and identity), despite setbacks, and to strive for an acceptable quality of life. Healthcare and physiotherapy in particular, in the experience of these participants, at best only partially supported their efforts to work towards a more homelike existence and, perhaps surprisingly, contributed to some of the participants' more negative experiences, particularly at times of existential flux when understanding and support would have been highly valued.

The findings reported here support other studies that identified co-existence as a critical feature of chronic illness. As discussed in chapter 2 (Understanding the Subjective Experience of Long-term Illness), Reynolds and Prior (2003) emphasised the interweaving of negative and positive strands of experience in the lives of women living with multiple sclerosis. Reeve et al. (2010) illustrated the way in which narrative flow and narrative fracture were intertwined in the lives of people living with terminal illness. The present study has illustrated how similar themes have emerged from accounts of people living with progressive cerebellar ataxia. This work has further emphasised that, for people living with ataxia, life is always in the making, it is neither fracture nor repair, positive or negative, but both. The good and the bad co-evolved and, in the middle of all of this, participants fashioned a life worth living not, on the whole, through adopting a "coping" strategy, a cognitive reflexive construct, but by engaging in the world, by saying, to paraphrase Heidegger (1966 [1955]:54-55), 'yes' but at the same time 'no'.

Dahlberg et al. (2009), Todres and Galvin (2010) and Galvin and Todres (2011) proposed a way of understanding and responding to chronic illness that perhaps advances the thinking in this field. The existential theory of well-being advanced by these scholars has some resonance with earlier work. For example, it is possible to see

parallels with sociological constructs such as biographical disruption (Bury, 1982), biographical repair and narrative reconstruction (G Williams, 1984), as well as post-traumatic growth (Tedeschi and Calhoun, 2004) and transformational coping (Kobasa, 1979; Maddi, 2006). However, by building this theory on the essential structures of human existence as articulated via the phenomenological concept of the lifeworld, Todres and Galvin (2010) and Galvin and Todres (2011) found a way to bring forth the complexity of people's lived experiences in a new way and, at the same time, opened up clearer paths towards understanding how it might be possible to recover a sense of homecoming within existential homelessness. The work presented here, based on a detailed in-depth analysis of the lived experience of progressive cerebellar ataxia, lends new empirical weight to the theory of existential well-being as proposed by Todres and Galvin (2010) and Galvin and Todres (2011).

#### **11.4 Strengths and Limitations of the Study**

Yardley's (2000, 2008) contextualised approach to the assessment of quality and rigour in qualitative research, and Smith's (2011a, b) principles for assessing the quality of IPA were used to interrogate key quality indicators for the present study. Yardley (2000, 2008) considered quality from the perspective of sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance.

Chapter 4 (Methodology) expounded the theoretical underpinnings of the study and by doing so attended to Yardley's (2000) concept of sensitivity to context. Furthermore, sensitivity to the intellectual history of research in this field was demonstrated in chapter 2 (Understanding the Subjective Experience of Long Term Illness) and chapter 3 (Literature Review). Ethical sensitivity was explored in chapter 2 with respect to conducting research *on* disabled people, chapter 4 (Methodology) regarding the construction of a "good" as well as a respectful interpretation of another person's life, and in chapter 5 (Method) with reference to ethical dilemmas encountered in the field.

For Yardley (2000), commitment refers to thoroughness in data collection, analysis and reporting. With regards to data collection, this study used an appropriate sample size consistent with an IPA. Commitment also refers to the researcher's responsibility for developing an appropriate level of competence and skill in the data collection methods and analysis used in the study. Developing competence in qualitative interviewing was described in chapter 5 (Method). The researcher also regularly attended the London IPA group and the annual IPA conferences in order to deepen her understanding of IPA, its theoretical underpinnings and the ways in which data could be analysed and presented.

Rigour is evaluated by the reader in terms of their assessment of the completeness of the data analysis and the depth of the interpretation, as considered below with specific reference to IPA. Transparency and coherence refer to the clarity and persuasiveness of the analysis and argumentation, and the extent to which the researcher has reflected upon, and discussed her influence on, the research. Reflexivity was addressed in chapter 1 (Introduction) and further examples were provided in the findings chapters. A final reflexive overview is offered below.

Smith's (2011a, b) principles for assessing the quality of IPA share much of Yardley's (2000, 2008) views for judging qualitative health research but with specific reference to IPA. The reader is firstly asked to judge whether the work is underpinned by the theoretical principles of IPA i.e. a commitment to the idiographic approach, attention directed towards an experiential account of significance to the participant(s), interpretative as well as phenomenological analysis and caution in moving towards general claims. Secondly, the reader might judge analytic transparency i.e. whether not only the content of data but also the meaning of data is clearly articulated (Smith, 2011a). Finally, a reader would consider whether the analysis is intelligible, credible, stimulating and, by way of quotations, sufficiently evidenced for each theme. Readers can only do this if they are able to fully connect with the analysis. Todres (1998:126) argued that researchers have a responsibility to help the reader 'to "stand before" the concreteness of the experience' and one way of doing this is by providing sufficient quotations to allow readers to judge the analysis for themselves. Specifically, extracts from at least three participants per theme plus an indication of overall prevalence or extracts from half the sample for each theme would constitute sufficient evidence for a study with twelve participants (Smith et al. 2011b). Noting the prevalence of a theme tells the reader about the extent to which a theme may be shared, but would not constitute good IPA unless accompanied by an interpretative narrative (Smith, 2011a). In addition, good IPA is thought to be characterised by having a clear focus, in-depth analysis, meaningful data and sound interpretation which illuminates the topic in a way that engages the reader (Smith, 2011b). This guidance was followed in the design and conduct of this study, analysing the data and presenting this thesis.

Additionally, it should also be possible, via an audit process, to trace the path the researcher has taken from raw data to the presentation of the final table of themes (Smith et al. 2009). The purpose of an audit is not to verify the reliability of the final account, but to confirm that it is coherent and credible (Smith et al. 2009). The iterative work involved in data analysis complicates this somewhat because the path from data to

themes is not linear. There is in fact a network of paths; these are well trampled, thoroughly criss-crossed, and stopping off points may have been revisited many times. However, as the process might be tortuous but not random, an independent auditor should be able to identify the route the researcher has taken, if provided with a sufficiently detailed map. For the purposes of this study, all stages of the analysis have been reviewed by the researcher's supervisors and all materials (from research proposal to final analysed account) are available for independent inspection.

Yardley's (2000) final dimension, impact and importance, refers to the ways in which the research opens up new ways of understanding, its utility and potential influence on others. The strong commitment to idiography may raise questions about the generalizability and clinical utility of IPA research. IPA's idiographic, interpretative and inductive stance does not confer strong predictive power and therefore limits the ability to generalise across settings or populations. However, small *n* studies are of value if they point out what was not previously known or understood, or if they reveal something unexpected which then causes the researcher and the reader to reflexively re-examine their assumptions or previously held positions (Smith et al. 1995; Smith et al. 2009; Packer, 2011). Stephens' (1982) concept of vertical generalizability is applicable in this context. It means that findings should be considered in terms of their ability to enhance understanding, enlarge insight, contribute to existing theories and the generation of new hypotheses (Johnson, 1997; Kearney 2001; Yardley, 2008). Thus, as with other forms of research, findings should be interrogated to see whether they provoke a re-evaluation of what was considered known or understood about the investigated phenomenon (Johnson, 1997). This process of comparing findings to experiential understanding is also consistent with IPA and its alignment with theoretical transferability (Smith et al. 2009).

As the first study to undertake a detailed analysis of the lived experience of progressive cerebellar ataxia, this research filled the gap in the literature identified in chapter 3 (Literature Review) and as such made a unique contribution to what was previously understood about this phenomenon. Using IPA, the findings that emerged were nuanced, highly contextualised and particular to participants in this study and therefore, as discussed above, only cautious claims are made towards vertical or theoretical transferability. The findings resonated with current literature about the lived experience of chronic illness and, as argued above, questioned and developed existing theory. For the practitioner, the value of this sort of research is that the findings may be attuned to issues which could be usefully explored in practice (Green and Britten, 1998).

Practitioners may consider, for example, whether the new understandings contribute to clinical reasoning processes or can be used to challenge conventional discourse or ways of thinking. These claims are made with particular reference to what has been learned from participants about their experience of the diagnostic process, their experiences of stigma, the value of exercise in its broadest sense and the novel understandings that emerged about the embodied experience of cerebellar ataxia. A further claim was made with respect to the way in which this study contributed to and qualified Svenaeus' (2000a, b, 2001, 2011) theory of illness as unhomelike being-in-the-world and Todres' and Galvin's (2010) theory of existential well-being. Furthermore, this study, as one of only a few IPA studies carried out by a physiotherapist, has shown that IPA is a useful means of answering psychologically orientated research questions of significance to physiotherapists. This study has made a further contribution by adding to the range of disciplines for which IPA can be profitably used. It has also been used to encourage physiotherapy researchers to consider using IPA to answer research questions of interest to the physiotherapy profession (Cassidy et al. 2011).

The following section considers and critiques particular aspects of the study and the bearing these may have had on the findings of the research. Recruitment of participants through membership organisations is justifiable and effective but it can raise concerns about the characteristics of participants. Kroll et al. (2007) argued that members of organisations often enjoy better connection to resources and support networks, tend to be knowledgeable about their condition and may show greater assertiveness in expressing their views and experiences. Furthermore, ethnic and social minority groups and people from low income backgrounds are less likely to be members of these organisations. The sample recruited for this study was not meant to be representative in terms of the UK population. However, it might be important to consider whether a different group of participants e.g. those from a minority ethnic background, would offer similar or different interpretations of living with ataxia. Also, for an IPA study, the sample was perhaps a little heterogeneous, for example, there was a large age range and impairment severity differed across the sample. Unsuccessful attempts were made to recruit participants from the NHS which might have allayed some of the concerns about recruiting only from Ataxia UK. Also, as this study investigated a rare and relatively unknown condition, it was not clear who, if anyone, would come forward to participate. The recruitment strategy was therefore intentionally broad but retained a specific focus directed at those who had lived with this condition for more than one year and who had also had some experience of physiotherapy. Having experience of physiotherapy as part of the inclusion criteria might also have influenced what emerged in super-ordinate

theme 5 (exercise and physiotherapy). As this study represents just the first step towards understanding what life might be like for people living with this complex condition, further research could be undertaken which addresses some of the limitations of this work with respect to the composition of the sample. New work might recruit participants who fulfil more stringent inclusion criteria to further explore the extent to which the findings offered in this study resonate with, or differ from, the experiences of particular groups.

This study was undertaken by a novice qualitative researcher and therefore it is highly likely that a more experienced researcher would have conducted the interviews and data analysis in a more expert fashion. In acknowledging that a PhD is, at least in part, an apprenticeship (Phillips and Pugh, 2010) and therefore a learning experience, the researcher primarily focussed on doing justice to participants' accounts and developing interviewing and data analysis skills. The meaning of progressive cerebellar ataxia and participants' experiences of healthcare and physiotherapy was developed with respect to the researcher's interpretation of the participants' interpretation of their lived experiences. Undoubtedly, another researcher using their own contexts would interpret the data differently (Packer, 2011). The findings presented in this study therefore do not claim to represent *the* truth or *the* meaning of the lived experience of progressive cerebellar ataxia. The researcher responded to the various ways in which these particular participants invited her to view their world as they saw it and lived it, but these responses were always interpreted through the researcher's particular "lens".

The effects on participants of being interviewed by a physiotherapist are unknown. It is possible that participants might have felt obliged to report positive experiences however, as noted in super-ordinate theme 5 (Exercise and Physiotherapy) this was not the case. It is also possible that this study attracted those who had particular concerns or grievances about physiotherapy that they wished to air. It is impossible to say whether participation in this study was motivated by these sorts of issues, but the participant information sheet and discussions with potential participants before recruitment stressed that both positive and negative accounts would be welcomed, and both good and bad experiences of physiotherapy were reported.

Certain aspects of this study could have been carried out differently, which might have improved the research process. As discussed in chapter 5 (Method) the researcher found conducting the interviews an initially difficult process. IPA demands a certain flexibility to allow participants to go "off script" to ensure the phenomenological

orientation of the study is followed (Eatough and Smith, 2008). However, this approach demands a certain confidence on the part of the researcher and the participant. Meeting the participant before the interview specifically to develop a good rapport and to discuss the purpose of the interview in more depth, rather than “parachuting in”, would have been difficult given the distances involved but other means of communication such as e-mail or the telephone could have been used to develop a stronger sensitivity to individual context (Kvale and Brinkman, 2009).

IPA has matured as an approach to undertaking phenomenological enquiry since 2007 when this study commenced, and over this time a deeper commitment to small samples, including *n* of 1, has been encouraged (Smith et al. 2009). Given the preliminary nature of this particular study, a sample size of 12 seemed reasonable in that it afforded a useful overview of issues that might be more closely investigated in future studies. Furthermore, appropriate attention was paid to individual accounts which retained the idiographic stance of IPA. Specific issues raised in this study, e.g. the impact of felt and enacted stigma, could be further investigated in a more focussed study with a smaller sample size. However, it is argued here that IPA remains the most appropriate means of answering the research questions. The reasons for this are both theoretical and pragmatic. IPA is directed towards understanding lived experience with the focus on highly circumscribed personal accounts (Smith et al. 2009) and this approach, as argued in chapters 4 (Methodology) and 5 (Method) was consistent with the research questions developed for the present study. This perspective is quite different from the type of macro-analysis encouraged by a qualitative approach such as grounded theory with its adoption of theoretical sampling methods and the testing and refinement of emerging theoretical explanations (Glaser and Strauss, 1967). IPA researchers are not opposed to making more general claims but do so only through a careful step-by-step approach (Smith and Osborn, 2008; Smith et al. 2009). This position seemed consistent with the nascent situation of qualitative research in this field where the findings reported here represent only the first step on the long ladder towards generalizability.

Secondly, and more pragmatically, other phenomenological approaches were not chosen for this study because they appeared less accessible to a novice researcher in this field. As discussed in chapter 4 (Methodology), whilst the differences between phenomenological approaches are a little fuzzy, IPA stands out because clear guidance is offered in a number of texts and papers (e.g. Reid et al. 2005; Smith and Osborn, 2008; Eatough and Smith, 2008; Smith et al. 2009) and via dedicated online groups and face to face meetings that support researchers new to IPA. However, given the way in

which this study developed and the overarching theme presented in this chapter with its emphasis on individual structures of the lifeworld, it is possible to see how future studies may benefit from taking a lifeworld approach such as that proposed by Dahlberg et al. (2008) or Ashworth (2003).

### **11.5 Final Reflexive Overview**

As reflexivity involves critical self-examination this section is written in the first person. As discussed in chapter 1, a reflexive stance was taken towards this study using the concept of hermeneutic reflection with respect to interpreting, understanding and explicating the position and influence of the researcher in the research (Finlay, 2003a; Shaw, 2010). Examples where reflexivity helped to identify or open up possible meanings were acknowledged throughout this thesis, particularly in the findings chapters and with reference to my initial concerns about using IPA as a physiotherapist who lacked formal psychology training.

Over the course of this study, I iteratively drew upon my personal contexts, as they came to light, and used them as a topic as well as a resource to interrogate the data and to critique the emergent findings (Packer, 2011). At the same time I attempted to step out of or, more accurately, shake off habitual ways of thinking in order to see my taken-for-granted understanding of ataxia in a new way. Finlay (2008) likened this complex process to a dance between exploiting past experience and setting it aside. In this sort of dance the steps evolve in an unpremeditated way, there is no routine as such, and it would be impossible to retrace the steps at the end of the dance. In describing phenomenological enquiry in this way, Finlay (2008) captured its fleeting and intangible qualities. The metaphor of a dance with improvised steps expressed the difficulty in pinpointing where insight or inspiration comes from during data analysis and why it is crucial to engage in critical self-analysis as a means of, at least partially, illuminating the influence of the researcher in the research.

My reflexive diary, used as device to glimpse into my past self, helped to retrace my steps, to understand, at least in part, where I had started and how my early concerns may have shaped data collection and analysis. For example, reading my diary entries from 2006 and 2007 showed that my anxiety about being a physiotherapist and not a psychologist acted on the research in two ways. First, I assumed that a psychology background would in some way give me better or more direct access to participants' experiences. I tried to be a psychologist, looking in the data for what I understood, at the time, as psychologically meaningful material. This sham-identity worked to undermine

the theoretical assumptions of phenomenological enquiry. I put imported ideas onto the data rather than interacting and working with the data in an authentic fashion. Second, as noted in chapter 1 and discussed further in chapter 6 (The Embodied Experience of Living with Progressive Cerebellar Ataxia), these endeavours led me to initially reject data that I interpreted as in any way relating to biomedicine or motor impairment. To me, at this early stage of data analysis, this sort of data could not be considered phenomenologically interesting, partly because ataxia related impairments were well explained in biomedical terms and also because I was unable to see how participants' descriptions of these impairments would add to the understanding of the lived experience of cerebellar ataxia.

My initial concerns have not changed. I still feel, as a physiotherapist doing IPA, that psychological and phenomenological insights are hard to come by. Good phenomenological work requires phenomenological sensibilities such as creativity and innovation, as well as having the faith and courage to take imaginative leaps in order to gain greater insight (Finlay, 2011). More specifically, IPA as an approach towards doing phenomenological research entails a particular way of thinking and seeing that cannot be easily encapsulated in a formal method (Smith et al. 2009). It is not surprising therefore that as a novice qualitative researcher, I initially sought comfort and security from formal structures and methods, and found the creativity and risk-taking required for IPA destabilising and difficult. However, writing at the final stages of this study, I can now recognise that rather than constraining this work, my professional background at least, if not my phenomenological expertise, may have allowed me to approach the study with a fresh perspective and to offer new insights. As a physiotherapist I am interested in the body. Once I had overcome my initial distrust of the signs and symptoms of ataxia as not being phenomenologically valid, I could allow the body to emerge. These perspectives and interests may partially explain the prominence of the embodied experience of progressive cerebellar ataxia in the findings.

Equally significant was my lack of awareness, at the start of the study, of my immersion in a particular world view that stood in opposition to what I was trying to achieve with this research. At first, I was simply aware that I perhaps overcompensated for what I now consider as my obvious biases. I knew that I would look for the positive in participants' accounts of their healthcare experiences, and I overcompensated for that assumption by initially focussing on reporting negative perceptions. These prejudices were addressed by going back to the data and starting again. However, what I eventually realised was that these preconceptions were just surface issues, relatively easy to grasp, make sense

of and address. In fact, these concerns represented only the tip of the reflexivity iceberg, much of what influenced the conduct of the study remained below the surface. It was only later that I understood my strongly positivist leanings and their potential for shaping the findings of this study. Firstly, I found it surprisingly difficult to move away from realist ways of thinking and interpreting the data. In adopting the persona of a qualitative phenomenological researcher I would experience moments of insight only to lose those insights and with them any sense of stability in my IPA research identity. I struggled to understand that what I was listening to and what participants were trying to impress upon me was not objective knowledge about the world as it “really is”. Staying with the understanding that participants were telling me something of their experience and their particular perceptions of the world, and accepting that what emerged was partial and uncertain was unsettling, and did not easily sit with what I now understand was my world view.

Secondly, as part of my positivist assumptions, I found even acknowledging that the study might reflect something about me, and that I was in fact “in” the data, deeply disturbing. Looking back, I now understand why my research diary is strangely impersonal and why I find writing in the first person so uncomfortable. I was clinging onto a positivist stance. Deep down, I believed that my involvement in the research would in some way contaminate the data. Although I could intellectually admit that in IPA the researcher is inevitably “in” the research, I found it difficult to acknowledge that “the researcher” was “me” and that it was me who shaped this thesis. These issues were at play and being dealt with throughout the course of this study. However, it seems to me that any “dealing with” was implicit or at least was not fully or concretely acknowledged. Prompts from my supervisors to re-think realist interpretations were taken to imply poor interpretative technique. It took a while to understand that simple inferences about technique hid more complex issues about my philosophical perspectives. These insights prompted me to question my assumptions about the data in a more profound way and not to simply try again with a section of problematic analysis. However, I experienced, at best, just fleeting moments of insight in the midst of the praxis of the research. I found it difficult to articulate what I had momentarily understood about my role in the research and the impact this may have. It is only now, at this late stage of the research that I feel that I can begin to make sense of it. The discovery of theories that captured what I thought I had understood about the lived experience of progressive cerebellar ataxia felt like a revelation. The idea that homelike experiences could be nested within existential unhomelikeness made sense. These concepts fitted with what I had tentatively understood from participants’ accounts. The insights gained from reading Merleau-Ponty

(2002 [1945]), Heidegger (1962 [1927]; 1966 [1955]; 1973 [1969]; 1993 [1971]), Svenaeus (2000a, b, 2001, 2011), Mugerauer (2008), Todres and Galvin (2010) and Galvin and Todres (2011) helped crystalize what I had already partially understood but initially at least found difficult to trust.

### **11.6 Summary**

This chapter has further discussed, synthesised and critically evaluated the overall findings of this study and has identified their unique contribution to knowledge. This new work, using fine grained idiographic analysis, has provided rich insights from a previously under-researched population and has potential to contribute to broader efforts to support people living with ataxia in the long term. The following chapter concludes this thesis by reflecting on what has been achieved and the implications for further research and practice.

## **Chapter 12**

### **Conclusion**

#### **12.1 Overview of the Study**

Before this study was undertaken, little qualitative research aiming to understand the subjective experience of this complex condition had been carried out which signified an important gap in what was known and understood about living with a progressive ataxia. During the course of the present study new qualitative studies were published (e.g. White et al. 2010; Daker-White et al. 2011; Walshe and Miller, 2011). However, as these studies did not make a detailed exploration of life with ataxia and, for the most part, had a rather narrow focus, the findings offered just fragmentary insights and brief glimpses into the worlds of people living with this condition. Therefore it was argued that, given the underdeveloped status of research in this field, further research which undertook an in-depth exploration of the lived experience of people with progressive ataxia was long overdue. The present study was considered valuable because it could make a contribution to the clinical field in terms of offering insights for practice. It could also add to the theoretical conceptualisation of the experience of long-term illness by offering new empirical data worthy of deeper consideration, as well as opening up new avenues for further research.

Using Interpretative Phenomenological Analysis, this study explored the experience of progressive cerebellar ataxia, healthcare and physiotherapy from the perspective of people who live with this condition. Phenomenological enquiry offered a means of going beyond what was ordinarily understood about life with ataxia, not only in terms of exploring the lived body but also in terms of gaining an in-depth, nuanced and finely grained appreciation of individuals and their world, a perspective neglected in previous work.

Twelve people living with progressive cerebellar ataxia were interviewed on one occasion. Participants lived in England (widespread locations) and were aged between 31 and 73 years. Time since diagnosis ranged from a minimum of one year to a maximum 23 years. Most participants had lived with symptoms if not a definitive diagnosis for over ten years, some for much longer. All interviews were recorded and transcribed. In-depth data analysis was undertaken following published guidance (Eatough and Smith, 2008; Smith and Osborne, 2008; Smith et al. 2009). The findings are discussed below with reference to the research questions.

## **12.2 Summary of the Main Findings with Respect to the Research Questions**

### **1. What is the meaning of progressive cerebellar ataxia for people who live with this condition?**

The meaning of ataxia for participants in this study is best understood not simply as a disruption to the physical body, but as a loss of the skilful interaction between body, self and world. Life with ataxia, and the constant adjustments that living with ataxia entailed, fundamentally disturbed the participants' sense of their being-in-the-world. They spoke of an on-going and at times profound sense of existential turmoil that disrupted their sense of who they were and what they were becoming. Participants struggled to hold onto the parts of their lives that they valued most; their sense of agency, personhood and identity. However, and often without meaningful support from healthcare practitioners, they worked to forge positive life experiences that not only reduced the salience of ataxia but also emphasised continuity, belonging, reciprocity and self-identity; ways of staying connected to the things and people that mattered to them in the particular contexts of their lives. At the same time they resisted, as far as they could, the extreme fatigue, stigma and social distancing that accompanied life with ataxia, and which further added to the burden of living with this condition.

At the highest level of abstraction, it was argued that the co-existence and co-employment of positive and negative life experiences could be understood through Heidegger's (1973 [1969]) conception of homelike and unhomelike existence. Participants' accounts suggested that through sustained effort and in the face of significant loss it was possible to retain a positive sense of self. At the same time, it was also, but not always, possible for participants to admit the distressing and hurtful aspects of living with ataxia, as well as their worst fears about their future lives, without becoming overwhelmed or letting these feelings and experiences hold sway. Therefore, participants in this study seemed, in a Heideggerian sense, to be able to build homelike qualities into unhomelike lives and this helped them to sustain lives that, at least in part, remained meaningful and self-affirming.

### **2. How do people living with a progressive cerebellar ataxia experience healthcare and physiotherapy in particular?**

Participants' accounts emphasised that in their experience healthcare was primarily orientated towards understanding and working on the impaired body. Particular emphasis was placed on a gruelling and frustrating diagnostic process which extended

and contextualised the findings of Daker-White et al. (2011). It seemed important to understand that, for participants in this study, diagnosis was experienced as a long-term event that extended beyond the initial consultation with the neurologist. Most participants were given a provisional diagnosis or had lived with ataxia for many years before finding out what type of ataxia they had. However, even a firm diagnosis offered very little in terms of prognostic certainty or treatment. An “idiopathic” diagnosis was common amongst participants and whilst this may be a useful description for healthcare professionals, it seemed to add to the chronic uncertainty experienced by participants in this study, and, by extension, to the burden of living with this condition. Furthermore, follow-up appointments which offered little, if any, concrete information about diagnosis, prognosis and treatment, deepened the frustration and dissatisfaction that accompanied hospital visits. The accounts also suggested that the psychologically troubling aspects of living with progressive ataxia, and the importance placed by participants on meaningful communication, were rarely addressed by healthcare practitioners. Instead of finding a hoped-for source of certainty and support, participants described feeling abandoned and fell back on their own resources in order to understand their condition and make sense of their lives.

An unexpected finding showed that physiotherapists seemed to prescribe exercise that also only focussed on the impaired body. Home exercises put an unwelcome salience on ataxia, and, because prescribed exercises were fatiguing and difficult to achieve independently, they seemed to further burden participants and add to their psychological and emotional suffering. Furthermore, rigid attachment to service models that left participants, for the most part, to manage exercise prescriptions independently for long periods of time, were generally described as unrewarding and unsustainable. Physiotherapists who provided long-term partnership working, responsive and flexible services, and individually tailored advice and support, particularly at times of physical and existential crisis, were singled out as offering the sort of therapeutic alliances that participants seemed to be looking for. Further work is needed, particularly research that directly explores physiotherapy in practice. In the meantime, the findings from this study support arguments put forward by Nicholls and Gibson (2010) and Wikström-Grotell and Eriksson (2012:434) that physiotherapists may need to reconsider their perhaps unwitting allegiance to the biomedical model, and to develop a model of physiotherapy that includes ‘not only physical, emotional, mental and socio-cultural but also existential domains’.

### **3. What is the meaning of exercise and activity participation for people living with progressive cerebellar ataxia?**

Participants in this study described self-selected exercise and physical activity as conferring multiple benefits that went beyond simple body maintenance, and emphasised the importance of understanding exercise and activity participation from a biopsychosocial perspective. Activity participation helped to sustain valued roles and relationships, and preserved a sense of belonging and continuity. Exercise contributed to well-being by combatting depression and stigma, and by helping to foster a positive sense of self. Participants' accounts suggested that they derived satisfaction from doing self-selected exercise that offered a challenge and a sense of achievement. Group activities, e.g. Pilates, craft work, dancing and team sports, strengthened the connection and authentic involvement with others by providing companionship and a sense of togetherness that had nothing to do with ataxia. Self-selected exercise diminished the salience of ataxia in participants' lives, and even if exercise yielded no impairment level benefits, participants described experiencing their body in a more positive way. Activities and exercise chosen by participants often contrasted sharply with physiotherapy prescribed exercise which emphasised the frailties of the body and an ataxia-dominant self-identity.

The findings from this study are new with respect to understanding the lived experience of ataxia and extend those of Mulligan et al. (2012) who reported similar benefits from self-selected exercise and activity participation for people with neurological disability. However, the disconnect between the meaning of self-chosen activities and physiotherapy-prescribed exercise might be considered as surprising new knowledge. These findings may provoke a re-evaluation of the way in which physiotherapy is provided for people living with progressive cerebellar ataxia, and indicate a potentially fruitful direction for further enquiry.

#### **12.3 Translational Relevance for Healthcare Practitioners**

Radley (1997:65) suggested that the practical implication of work that discloses the lived experience of illness is that it 'reveals the limitations of interventions that rest upon the division of body, self and society into separate spheres.' Healthcare practitioners who understand how these concepts are bound together in the lives of the people concerned will be better placed to alleviate suffering and contribute to the maintenance of health. Research questions 2 and 3 focussed on physiotherapy and on healthcare practice

more generally, and, by doing so, identified findings that reach beyond physiotherapy to other healthcare fields.

Participants in this study described a disruption to the body that could not be separated from disruptions to their sense of self and themselves in the world. Ataxia was encountered in a lifeworld; understood in a context of self, family, society, projects and action. The practical application of Todres and Galvin's (2010) theory of existential well-being, lies in facilitating possibilities for finding a more homelike way of being, at both existential and literal levels. Healthcare practitioners may find this concept a useful template for working with people living with ataxia. This is because, as argued by Dahlberg et al. (2009), a lifeworld approach allows due attention to be paid to the vicissitudes and suffering in people's lives but also highlights a fundamental but often hidden potential for well-being. In this sense, both wellness and illness can be meaningfully addressed, because as suggested by the findings of this study they co-evolve.

It is argued here, with reference to theoretical generalizability, that a range of healthcare practitioners (GPs, neurologists, specialist nurses, occupational therapists and counselling psychologists, as well as physiotherapists) may, by interrogating the findings of this study and by adopting Todres' and Galvin's (2010) existential theory of well-being, find themselves better equipped to address the concerns and priorities of people living with progressive cerebellar ataxia who seek their advice and support. GPs, neurologists and geneticists, may, for example, foster more meaningful and helpful relationships with their patients if they seek to deepen their understanding of the vulnerability, anxiety and frustration that accompanies life with ataxia, and which seems to be intensified through the lengthy and problematic diagnostic process. It may also help to openly discuss and admit the limitations of medicine whilst fostering a genuine sense of collaboration and alliance that prioritises patients' perspectives. This could be achieved not by diminishing the significance of ataxia but by helping individuals make sense of what is happening to them in the context of their lives. This kind of undertaking may also involve appropriate referral to other healthcare practitioners such as occupational therapists and health psychologists. As these findings add to those of Daker-White et al. (2011), it may now be time for neurologists and people living with ataxia to work together to find better ways of supporting people as they go through what appears to be a lengthy and discomfiting diagnostic process.

Healthcare practitioners (therapists, nurses and doctors) are also well placed to help people living with progressive ataxia to recognise and manage their own cognitions

about stigma, and to adopt approaches towards managing stigma that best fit their particular circumstances and experiences. Stigmatised people may need to try out several problem solving strategies before they find one that helps them achieve their goals and which allows them to hold onto what they value most in their lives (Miller and Meyers, 1998). Active problem solving and cognitive restructuring might therefore be best considered as skills that are acquired over time. It would be important for clinicians to be attentive to the variety of ways in which people living with progressive cerebellar ataxia respond to stigma-related stress (as detailed in super-ordinate theme 2) as well as being sensitive to the ways in which stigma interacts with other dimensions of experience. For example, using a walking stick may improve gait but may also place an unwelcome emphasis on the impaired or deteriorating body that people living with ataxia may find difficult to accept. This study has shown that healthcare practitioners' understanding of stigma should be grounded in and tailored to the distinctive practical and existential concerns of individual patients. This suggests that support and guidance should be responsive to fluctuations in a person's ability to apply strategies to overcome stigma, for example in the face of further physical deterioration.

### **12.3.1 Specific Implications for Physiotherapists**

This study illustrated the rich insights that can be gained from adopting a phenomenological perspective as compared to a more biomedical approach towards understanding the impact of cerebellar ataxia on individuals' lives. Through combining a traditional orientation towards the physical body with an understanding of the 'body-as-lived' (Marcum, 2004:312; Hammell, 2006), physiotherapists might re-consider the importance of home exercises and the potential value of supporting patients to participate in self-selected activities and exercise. This sort of exercise may confer physical benefits which also contribute more broadly to subjective well-being and a positive sense of self. Given the lack of evidence for physiotherapy interventions and understanding the negative impact of ataxia on everyday life experience, it may be useful for physiotherapists to think beyond impairment-level management strategies and to embrace exercise opportunities that have more chance of generating positive life experiences and positive self-image.

Physiotherapists are in a position to both appreciate the personal significance and complexities of patients' lived experiences and to offer practical support. For example, consistent with the views of others living with long-term neurological conditions (Bernard et al. 2010), it seemed important for participants in this study to develop therapeutic alliances with physiotherapists, to consult them on an equal footing, bringing in their

expertise in living with this condition whilst consulting expert others to help develop knowledge, to answer specific questions and to respond to and offer support at times of crises. These findings suggested that physiotherapists might profit from understanding that participants in this study were not looking for a technical fix or cure for their condition. Good communication skills, being listened to and understood was also central to what was valued in the therapeutic relationship. Therefore therapists and perhaps physiotherapists in particular may need to reconsider how services can be configured to meet these needs and whether there is an appropriate emphasis on helping people with ataxia flourish rather than on fixing impairments.

These practice implications can only be considered if the findings from this work are disseminated to relevant audiences (practitioners, people living with ataxia, funding bodies and charitable organisations). Appendix L lists the various ways in which this work has been disseminated to date. Two papers have been published, mainly addressing a physiotherapy readership and further publications in peer reviewed journals are anticipated.

#### **12.4 Implications for Future Research**

Research focussing on the development of physiotherapy interventions for people living with progressive cerebellar ataxia is in its infancy. Researchers conducting studies without understanding that self-selected exercise may be a force for promoting well-being in its broadest sense, and that prescribed home-exercises possibly add to the burden of life with ataxia, may naïvely pursue a prescriptive home-exercise intervention that risks failure for psychosocial rather than biomedical reasons. A more focussed IPA could be undertaken to explore the role of exercise and physical activity and the possible facilitators and barriers to participation. This new work could be informed by the findings of the present study and may also be usefully incorporated in the design of mixed methods research, as part of a larger study looking at the development of physiotherapy interventions for people living with progressive ataxia.

IPA would also be well placed to explore family dynamics which were not the focus of the present study. This may be a fruitful topic for further qualitative enquiry because it would allow a deeper consideration of the inheritable aspects of living with a progressive ataxia which were only partially glimpsed in this study. Furthermore, this study showed that instead of being supportive, as might be expected, some participants felt discredited by close family members. Further qualitative enquiry with family groups may help to shed light on how stigma is realised and dealt within the family. Insights from this sort of

research may provide a more nuanced understanding of this topic and identify ways in which individuals and families could manage stigma and stigmatising experiences in a positive way, as well as how they manage anxieties associated with the genetic transmission of this condition.

The findings of this study could be taken to people living with ataxia. Formal methods, e.g. focus groups, could be used to discuss the findings to see whether they resonate with the views of other people living under similar circumstances. This approach may lead to further elaboration of particular findings from the present study. These amplifications may then contribute to a corpus of evidence which in turn may speed up the often incremental translation of research findings into clinical practice. Further avenues for research may also be identified. Participatory action research takes a more emancipatory approach (White et al. 2004). The findings from this research could be discussed by people living with ataxia who could then, as co-researchers, identify and prioritise future projects. These projects may focus on changing aspects of participants' lives that are found to be particularly distressing or disempowering. Done well, involvement in this type of research, rather than being burdensome can be life-enhancing (Nelson et al. 1998) particularly when involvement results in tangible differences in areas where participants feel most change is needed e.g. in the healthcare setting. Further research, where neurologists, specialist nurses, psychologists and patients work together to explore possible ways of changing practice in ways that help patients live with uncertainty, seems timely.

Focus groups with physiotherapists have already been undertaken by the author in order to explore contemporary practice and participants' experiences of working with people living with progressive cerebellar ataxia. Further analytical work is required but this new study should provide a useful comparison between the perceptions of physiotherapy illustrated in the present study and the perspectives of physiotherapists. A progression of this study might involve an observational arm that explores the therapeutic relationship between physiotherapists and people living with ataxia in practice. Conversation analysis may be an appropriate methodology for this type of research (Drew, 2003). The study would focus on naturally occurring interactions i.e. between physiotherapists and people living with ataxia in a clinic situation. Data analysis would attend to the context of the conversation, looking specifically at how participants understand and respond to each other. This sort of work would first need to establish whether there is a mismatch between what physiotherapists understand as their role in supporting people living with ataxia, what is actually delivered, and what is perceived by patients, and then, secondly, untangle the reasons for any apparent incongruence.

## 12.5 Summary

This study has offered new, highly detailed and contextualised insights into the lived experience of progressive cerebellar ataxia. The careful application of IPA suggested that participants made sense of their lives in a variety of ways depending on their personal contexts. At the highest level of abstraction it was shown that although life with ataxia could threaten the very being of each participant and their attachment to the things and people that gave their life meaning, they had also, generally without the support of healthcare practitioners, and with much hardship and effort, found ways to build self-affirming and life-affirming experiences into their everyday living. These new findings may have resonance for several healthcare practitioners, not only physiotherapists but also neurologists, occupational therapists, geneticists, counselling psychologists, GPs and specialist nurses. Furthermore, this study has lent empirical weight to Todres and Galvin's (2010) existential theory of well-being, an emerging and potentially useful theoretical construct for healthcare practice. The empirical data and findings from the present work were also used to question and qualify Svenaeus' (2000a, b, 2001, 2011) view that alienation is an inevitable part of the experience of long-term illness. Finally, the present study identified clear paths for further research. Such work might not only involve further IPA studies but also other ways of taking the findings of this study forward e.g. into mixed methods as well as more emancipatory forms of enquiry. Taken together, this work and the implications derived from it provide a valuable addition to research in this field.

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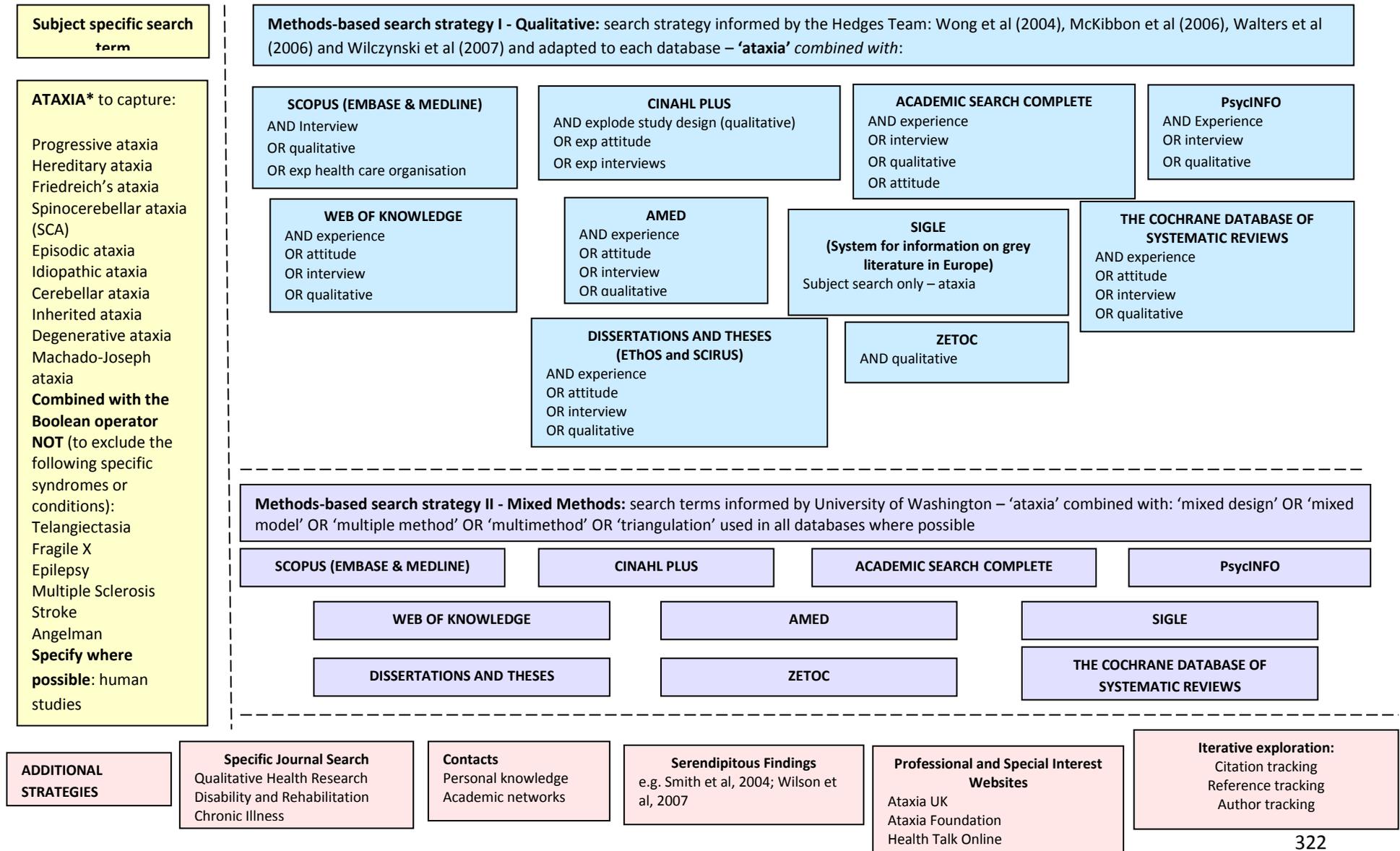
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## Appendix A1: Overview of the Literature Search Strategy



**Appendix A2: Results of Database Searches and Number of Selected Papers from Each Source**

<b>Data Base (combined qualitative and mixed methods searching)</b>	<b>Number of Identified Studies</b>	<b>Number of Selected Studies</b>
Academic Search Complete	73	4
AMED	1	0
CINHAL Plus	15	1
Cochrane	0	0
EThos (British Library)	0	0
PsycINFO	57	1
SCOPUS (EMBASE & MEDLINE)	756	1
SCIRUS	283	0
SIGLE	19	0
Web of Knowledge	2086	5
ZETOC	7	0
Other sources (citation tracking, serendipity)		10
Chronic Illness (2005-2012)	2	1
Qualitative Health Research (1991-2012)	3	0
Disability and Rehabilitation (1978-2012)	103	2
Replications		7
<b>Total <i>n</i></b>	<b>3405</b>	<b>26</b>
<b>Total considered in this review</b>		<b>19</b>

## Appendix B: Location of Selected Papers from the Literature Search

Paper ( <i>n</i> = 19)	Located In
Abele and Klockgether, 2007	Citation tracking
Ataxia UK 2007a, b	Ataxia UK
Box et al, 2005	Ataxia UK
Boutté, 1987, 1990, 1992	Citation tracking
Brown, 2010	Academic Search Complete
Cano et al, 2009	CINHAL, Medline, Web of Knowledge
Daker-White et al, 2011	SCOPUS, PsycINFO, Web of Knowledge, Chronic Illness, Academic Search Complete
D'Ambrosio et al, 1987	Disability and Rehabilitation (International Disability Studies)
Drake and Guillory, 2001	Academic Search Complete
Hess et al, 2009	Academic Search Complete, Web of Knowledge
López -Bastida et al, 2008	Citation tracking
Powell et al, 2010	Web of Knowledge
Serrano-Aguilar et al, 2009	Web of Knowledge
Walshe and Miller 2011	Disability and Rehabilitation
Wilson et al, 2007	Serendipitous
White et al, 2010	Serendipitous

## Appendix Ca

School of Health Sciences and  
Social Care

### Research Ethics Committee

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18 January 2007

Proposer: Elizabeth Cassidy

Title: **An Exploration of Contemporary Physiotherapy Practice for People with Ataxia:  
The perspectives of clients and physiotherapists**

The School Research Ethics Committee has considered the amendments recently submitted by you in response to the Committee's earlier review of the above application

The Chair, acting under delegated authority, is satisfied that the amendments accord with the decision of the Committee and has agreed that there is no objection on ethical grounds to the proposed study. Approval is given on the understanding that the conditions of approval set out below are followed:

- *The agreed protocol must be followed. Any changes to the protocol will require prior approval from the Committee.*

**NB:**

- **Research participant information sheets and (where relevant) flyers, posters and consent forms, should include a clear statement that research ethics approval has been obtained from the School of Health Sciences and Social Care Research Ethics Committee.**
- **Approval to proceed with the study is granted subject to receipt by the Committee of satisfactory responses to any conditions that may appear above, in addition to any subsequent changes to the protocol.**

David Anderson-Ford  
Chair, Research Ethics Committee  
School of Health Sciences and Social Care

## Appendix Cb Further Approval

School of Health Sciences and  
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## Research Ethics Committee

26 March 2007

Proposer: Elizabeth Cassidy

Title: **An Exploration of Contemporary Physiotherapy Practice for People with Ataxia:  
The perspectives of clients and physiotherapists**

The School Research Ethics Committee has considered the further amendments recently submitted by you in relation to the above application

The Chair, acting under delegated authority, is satisfied that there is no objection on ethical grounds to the proposed study. Approval is given on the understanding that the conditions of approval set out below are followed:

- *The agreed protocol must be followed. Any changes to the protocol will require prior approval from the Committee.*

### **NB:**

- **Research participant information sheets and (where relevant) flyers, posters and consent forms, should include a clear statement that research ethics approval has been obtained from the School of Health Sciences and Social Care Research Ethics Committee.**
- **Approval to proceed with the study is granted subject to receipt by the Committee of satisfactory responses to any conditions that may appear above, in addition to any subsequent changes to the protocol.**

**David Anderson-Ford**  
**Chair, Research Ethics Committee**

## **PARTICIPANT INFORMATION SHEET**

**Title of Project: An exploration of contemporary physiotherapy practice for people with ataxia: the perspectives of clients and physiotherapists**

### **Invitation to Participate:**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

- Part 1 tells you the purpose of the study and what will happen to you if you take part
- Part 2 gives you more detailed information about the conduct of the study

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

### **What is the purpose of the study?**

Although physiotherapy is considered an important part of helping people with ataxia there is very little research to guide physiotherapists towards the most effective and useful ways of treating people with ataxia.

We would like to ask people with ataxia about their experiences of physiotherapy, what they have found useful and not so useful and what it is like to live with ataxia. We hope that this information would help improve physiotherapy services and help others to understand what living with ataxia is like.

This study will also ask physiotherapists about their experiences in treating people with ataxia, what ideas they base this treatment on and how they organise the services they provide.

We hope that this study will also identify areas for future research that are relevant to physiotherapy and people with ataxia.

### **Am I eligible to take part?**

If you are over the age of 18, have had cerebellar ataxia for more than six months, you do not have any other neurological condition e.g. multiple sclerosis, and you are able to participate in a conversation in English, you would be eligible to participate in this study. You may have responded to information on the Ataxia UK website or been given information about this project at a local branch meeting.

It is anticipated that about 36 people with ataxia and 36 physiotherapists will be recruited to this study.

### **Do I have to take part?**

No. It is up to you whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your future treatment in the NHS or involvement with Ataxia UK in any way.

## **What will happen to me if I take part?**

1. If you are interested in this study you can contact us by e-mail or telephone (see below). One of the researchers will discuss the study with you and answer any questions you may have. The discussion would normally be over the phone. We would also be happy to contact you by e-mail.
2. We will ask your permission to inform your GP about your potential participation in this study.
3. We would ask you to let us know if you have any special requirements e.g. wheelchair access.
4. There may be a wait involved of up to 3 months whilst we recruit other people to the study. We would keep you informed of our progress on recruitment.
5. You would then be invited to attend a focus group (group discussion) with a minimum of 1 and a maximum of 11 other people with ataxia. This would take place either in the London region at the headquarters of Ataxia UK, Brunel University or another location in the UK acceptable to the participants and the researchers if more convenient.
6. You would then attend one focus group. You will have the opportunity to ask further questions about the study and if you are happy to participate you will be asked to sign and complete a consent form. We would then ask you to complete a brief form about the type of ataxia you have, how long you have been diagnosed for, your age and occupational status (in work, unemployed, retired). The researchers would be able to help you complete the form if required.
7. Two members of the research team will lead the focus group and introduce topics for everybody to discuss. These will be concerned with for example the experience of living with ataxia, as well as experiences of physiotherapy and recommendations to improve services. The group will be asked to summarise their discussion at the end of the focus group. Because of the nature of the focus group it is important that you are happy discussing topics in English.
8. The focus group is expected to last for 1 hour and completion of the consent and background information forms a maximum of 30 minutes. Total time required being no more than an hour and a half.
9. The focus group will be digitally recorded and transcribed into a typed up version. Digital recordings will be stored on a computer with password protection. Confidentiality is assured from the researchers, you will not be able to be identified from the recordings. The participants in the focus group will be asked to maintain confidentiality for each other. Only the researchers and the transcriber will have access to the recordings. The recorded information will be used to analyse the discussion.
10. In the writing up of the research direct (verbatim) quotations will be used to illustrate what was said. Confidentiality will be maintained because you will not be able to be identified from the quoted passages.

## **Expenses and Payments**

Travel expenses incurred due to your participation in this study will be reimbursed.

**What if my mobility problems stop me coming to the focus group?**

If this is a problem, and if acceptable to you, one or two members of the research team would come to your home to conduct an interview with you. Although this approach would not involve the discussion element of the focus group we would conduct the interview after the first couple of focus groups so that we could tell you about the kind of things that were discussed so that you could comment on it if you wanted to.

The procedure would be the same as above – completion of the consent form and background information form, recorded interview and publication of direct quotes (verbatim) that would be anonymised. The interview would last up to 1 hour with a further 15 minutes for completing the consent form and background information form.

**What if I have difficulty with my speech / or use an assistive device?**

If this is a problem, and if it acceptable to you, two of the research team would come to your home to conduct an interview with you. Although this approach would not involve the discussion element of the focus group we would conduct the interview after the first couple of focus groups so that we could tell you about the kind of things that were discussed so that you could comment on it if you wanted to.

The procedure would be the same as above – completion of the consent form and background information form, recorded interview and publication of direct quotes (verbatim) that would be anonymised. The interview would last up to 1 hour with a further 15 minutes for completion of the consent form and background information form.

**What are the disadvantages or risks of taking part?**

The main risk is the potential for distress due to the nature of the experiences being discussed. Furthermore some participants may feel uncomfortable or embarrassed by the opinions they hold or their lack of opinion on topics on which they feel they are being expected to have opinions.

If you become worried or distressed during the focus groups you'll be asked whether you would like to continue or take a break from the discussion. Members of the research team, who through their profession have experience in supporting people who are distressed, will give you support in the first instance.

If you prefer to be interviewed in your own home due to difficulty with mobility or communicating in group situations it is advisable to have a friend or relative available.

**What are the possible benefits of taking part?**

We cannot promise that the study will help you but the information we get might help improve the treatment of people with cerebellar ataxia in the future.

**What if there is a problem?**

Any complaint about the way you have been dealt with during the study or any possible harm you may suffer will be addressed. The detailed information on this is given in part 2.

**Will my taking part in the study be kept confidential?**

Yes. All the information about your participation in this study will be kept confidential. The details are included in part 2.

**Who is conducting the research?**

The principle investigator of this study is Elizabeth Cassidy MCSP, MSc, Lecturer in Physiotherapy, Brunel University. She is undertaking this research as part of her PhD at Brunel University. Her supervisors are Dr Frances Reynolds and Prof. Lorraine De Souza. Elizabeth can be contacted on 01895 268736 or [elizabeth.cassidy@brunel.ac.uk](mailto:elizabeth.cassidy@brunel.ac.uk)

The other researchers are:

Sandra Naylor Grad. Dip. Physiotherapy, MEd, Director of Physiotherapy, Brunel University

Dr Frances Reynolds, BSc, PhD, Senior Lecturer in Psychology, Brunel University  
Anbreen Khan BSc, MSc Private Practitioner in Neurorehabilitation

For complaints please contact:

David Anderson-Ford, Chair of the Ethics Committee, Brunel University, 01895 268 731  
david.anderson-ford@brunel.ac.uk

**This completes Part 1 of the Information Sheet.**

**If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.**

## **Part 2**

### **What if relevant new information becomes available?**

Sometimes during the course of a research project new information becomes available about the treatment that is being studied, in this case physiotherapy. If this happens the researcher will tell you about it but it is unlikely to affect the study.

### **What will happen if I don't want to carry on with the study?**

You are free to withdraw from the study at any time without affecting your future involvement in any other research, physiotherapy or your participation in activities supported by Ataxia UK. If you wish to stop being involved in the focus group once it has started you are free to withdraw at any point. If this happens we would use your contribution up until the point of withdrawal.

### **What if there is a problem?**

#### **Complaints:**

If you have a concern about any aspect of this study, you should speak with the researchers who will do their best to answer your questions (Elizabeth Cassidy, telephone 01895 268736). If you remain unhappy or wish to complain formally, you can do this through Brunel University (David Anderson-Ford, Chair of the Research Ethics Committee, Brunel University, telephone 01895 268 731).

#### **Harm:**

In the event that something goes wrong and you are harmed during the research there are no special compensation arrangements. If you are harmed and this is due to someone's negligence then you may have grounds for legal action for compensation against Brunel University but you may have to pay your legal costs.

### **Will my taking part be kept confidential?**

Yes. All information collected about you during the course of the study will be kept strictly confidential. Our procedures for handling, processing, storage and destruction of data are compliant with the Data Protection Act 1998. However, if evidence of malpractice came to light during the focus group, in line with research guidelines confidentiality would have to be broken. We would tell you at the time if we thought we needed to do this and let you know about what would happen next.

You will be asked to provide us with contact details. This will most likely be your name, address, and telephone number, e-mail address if you have one and the name and address of your GP. You will also be asked to provide us with information about yourself on the background information form. This information will be stored securely on a computer within Brunel University. The files will be password protected. If you contact us

by e-mail your e-mail address will be stored with your other personal data. We will delete your e-mails and their replies from the researcher's e-mail application. Your name and address will be stored on separate files and a code used to identify you if required. The custodian of the data will be the Principle Investigator, Elizabeth Cassidy. The information will only be used to contact you about this research project. General information about the age range of our participants and how long they have had ataxia for will be used in the writing up of the study. The Principle Investigator will have access to this data.

As explained above, the focus group discussions will be recorded and transcribed in full. You will not be able to be identified from the recordings. The recordings will be downloaded and stored securely on password-protected files as focus group 1, focus group 2 etc. All researchers and the transcriber will have access to this data. Our sponsors and regulatory bodies may also wish to view this data to check that the study is being carried out correctly.

Your contact details will be destroyed upon completion of the study. The recorded and transcribed data will be retained for 15 years and will then be disposed of securely.

### **What will happen to the results of the study?**

We aim to publish the findings from the study in scientific journals, which are particularly relevant to physiotherapists. We also aim to feedback the findings of the study to the participants both in writing and through the Ataxia UK website. Please let us know if you would like to be sent a written summary of the findings of the study.

You will not be able to be identified in any report/publication although we will be using direct quotes from the discussion to illustrate what was said.

### **Who is organising and funding the research?**

Ataxia UK is funding this research and it is being conducted under their guidance and that of Brunel University.

None of the researchers or local collaborators will receive payment for your inclusion in this study.

### **Who has reviewed the study?**

The Research Ethics Committee at the School of Health Sciences and Social Care, Brunel University, has reviewed the study and granted ethics approval.

Thank you for considering taking part in this research and taking the time to read this information sheet.

You can keep hold of this information sheet and if you are interested in participating in the study we would ask that you contact the Principle Investigator Elizabeth Cassidy (Betty) to discuss it further: telephone: 01895 268736 or email:

[elizabeth.cassidy@brunel.ac.uk](mailto:elizabeth.cassidy@brunel.ac.uk)



Contemporary physiotherapy practice for people  
with ataxia: the perspectives of people with ataxia and  
physiotherapists

## VOLUNTEERS REQUIRED

We are looking for people with ataxia to participate in a discussion group with other people who have ataxia about topics such as their experience of living with ataxia, strategies used to maintain activity levels and experiences of physiotherapy treatment.

If you are over 18 years old, have been diagnosed with cerebellar ataxia for more than 6 months and are interested in participating please contact Elizabeth Cassidy, Lecturer in Physiotherapy at Brunel University, for more information. Telephone 01895 268736 or e-mail [elizabeth.cassidy@brunel.ac.uk](mailto:elizabeth.cassidy@brunel.ac.uk)

Research ethics approval has been obtained for this study from the School of Health Sciences and Social Care Research Ethics Committee, Brunel University.



## **Appendix Ga Draft Topic Guide version 1**

### **Draft Questioning Route 11 January 2007**

#### **Introduction**

- Thank participants for their attendance
- Introduce the researchers and their roles during the focus group
- Overview of the research and further opportunity to ask questions
- Inform participants about how the focus group is likely to run and what is expected of participants with particular reference to confidentiality
- Signing of consent forms
- Completion of background information form
- Housekeeping information; toilets, eating and drinking, use of audio equipment, fire exits etc.

#### **1. Focus Group (people with ataxia)**

**Opening questions:** getting people to talk and feel comfortable (not for analysis)

For example: Tell us who you are and how you heard about this project

#### **Topic 1: Experiences of physiotherapy (interventions and service provision)**

##### **Introductory Questions**

These questions will allow the participants to describe how they view physiotherapy and will give the facilitators clues about participants' views.

For example: 'What is the first thing that comes to mind when you hear the word physiotherapy?'

##### **Transition Questions**

These questions move the topic on to the key questions that inform the study and participants become aware of how others view the topic.

For example: Tell us about the process of being referred to a physiotherapist – was this straight forward?

Could you tell us about how physiotherapy has been provided, for example do you get to see a physiotherapist very often?

##### **Key Questions:**

These are the questions that are fundamental to the study and will have more time allocated to them than the other questions.

For example: Could you describe the kinds of things you have done in physiotherapy?

What things have you found useful about physiotherapy?

What things have you found less useful?

Could you tell us about any other sort exercise that you have found helpful?

##### **Ending Question:**

If you had a chance to give advice to physiotherapists about the most important things to consider when working with someone with ataxia what would it be?

#### **Topic 2 Experiences of living with ataxia and maintaining valued occupations**

##### **Transition Questions**

For example: Moving on from physical activity and physiotherapy, could you tell us about other activities in your daily life that are important to you?

**Key Questions:**

For example: Have you needed to change the way you do these things because of ataxia? If so, in what ways?

Has anything that you've learnt or done been particularly useful in being able to continue with these?

Have any other groups or organisations or people been useful or unhelpful in supporting you doing the things that are important to you?

If you met someone who knew very little about ataxia how would you describe the experience of living with ataxia?

**Ending Question:**

We would like this study to reflect your experience of living with ataxia and your experiences of physiotherapy. Is there anything that we've missed? Is there anything that you came wanting to say that you didn't get a chance to say?

**Summary**

Before bringing the group to a close, the researcher will summarise the key points made during the group and check with the group that these were captured accurately.

Refreshments will be available and breaks taken at a convenient time during the discussion.

## Appendix Gb: Draft Topic Guide v2

### Draft Annotated Topic Guide Mapped to Research Objectives 20 February 2007

#### Introduction

- Thank participants for their attendance
- Introduce the researchers and their roles during the focus group
- Overview of the research and further opportunity to ask questions
- Inform participants about how the focus group is likely to run and what is expected of participants with particular reference to confidentiality
- Signing of consent forms
- Completion of background information form
- Housekeeping information; toilets, eating and drinking, use of audio equipment, fire exits etc.

#### 1. Focus Group (people with ataxia)

##### **Topic: getting people to talk and feel comfortable, also exploring motives for participation**

Could you tell everyone who you are (first name only) and why you're interested in being involved in this study?

##### **Topic: Experiences of living with ataxia and maintaining valued occupations**

**Key Questions** These are the questions that are fundamental to the study and will have more time allocated to them than the other questions.

I'd like you to close your eyes and think for a moment about what it's like to have ataxia; ...if you met someone who knew very little/nothing about ataxia think about how would you describe what living with ataxia is like.

OK I'd like you to open your eyes and describe what it's like to live with ataxia.

Probes:

Does anyone have anything else to add to the picture?  
Has ataxia affected your relationships with other people?  
How about things like aims, hopes, ambitions

Can you describe (in more detail) how ataxia has affected your day to day activities?

Probes e.g. the way you like to spend your time, the things you feel you like doing, your role at home or at work, the things that you feel are important for you to do?

Could you tell us about any day to day activities that give you particular satisfaction?

#### **BOLD = Research aims and objectives**

GREY = Theoretical underpinning, thoughts about what the research is trying to uncover/elicit and the mechanisms used to do that

What are you trying to get at here; more than just a loosener; underlying motives, start telling the researcher something about the context/make up of the group. Should be an easy opening which is not normally analysed (according to Krueger and Casey) but the response to this would be quite interesting in describing the group.

#### **To explore experiences of living with ataxia as explained by people with ataxia**

**...focussing on valued occupations**

**...strategies used to maintain occupations**

Have you needed to change the way you do these things because of ataxia? If so, in what ways?

Has anything that you've learnt or done been particularly useful in being able to continue with these?

Have you taken up any new roles or activities?

Have any other groups or organisations or people been helpful or unhelpful in supporting you doing the things that are important to you?

**Transition:** We're now going to move on from activities in your daily life that are important to you to physical activity and physiotherapy.

### **Experiences of physiotherapy (interventions and service provision)**

#### **Theme: experience and perspectives of physiotherapy**

What is the first thing that comes to mind when you hear the word physiotherapy?

So how would you define physiotherapy?

#### **Transition Questions**

These questions move the topic on to the key questions that inform the study and participants become aware of how others view the topic.

Tell us about the process of being referred to a physiotherapist – (was this straight forward?)

Could you tell us about how physiotherapy has been provided, for example do you get to see a physiotherapist very often?

#### **Key Questions**

##### **Theme: Contemporary practice**

Could you describe the kinds of things you have done in physiotherapy?

Has physiotherapy been helpful? (Probes: have you noticed changes in your physical ability (physical), ability to do the things or activities that interest you most (occupational), what about other benefits, how you feel about yourself or in yourself? (psychological))

Did anything about physiotherapy surprise you?

What is most supportive about physiotherapy?

What are the barriers to receiving adequate physiotherapy?

Could you tell us about any other sort exercise that you've found helpful? (Gym, stretches, swimming)

**Transition from the general to the specific experiences of living with ataxia to experiences of physiotherapy**

**To explore experiences and perspectives of physiotherapy**

Defining physiotherapy: why use this question to meet this aim?

**...experiences and perspectives**

**...to record the experiences of physiotherapy services**

**...to record contemporary practice**

**...strategies used to maintain valued occupations and activities**

What barriers to doing your own exercise have you experienced?

**Ending Question:**

If you had a chance to give advice to physiotherapists about the most important things to consider when working with someone with ataxia what would it be?

**Ending Question:**

We would like this study to reflect your experience of living with ataxia and your experiences of physiotherapy. Is there anything that we've missed? Is there anything that you came wanting to say that you didn't get a chance to say?

**Summary**

Before bringing the group to a close, the researcher will summarise the key points made during the group and check with the group that these were captured accurately.

Refreshments will be available and breaks taken at a convenient time during the discussion.

## Appendix Gc Draft Topic Guide v3

### Draft Topic Guide

#### Introduction

- Thank participants for their attendance
- Introduce the researchers and their roles during the focus group
- Overview of the research and further opportunity to ask questions
- Inform participants about how the focus group is likely to run and what is expected of participants with particular reference to confidentiality
- Signing of consent forms
- Completion of background information form
- Housekeeping information; toilets, eating and drinking, use of audio equipment, fire exits etc.

#### 1. Focus Group (people with ataxia)

**Topic: getting people to talk and feel comfortable, also exploring motives for participation**

**Could you tell everyone who you are (first name only) and why you're interested in being involved in this study?**

**Topic: Experiences of living with ataxia and maintaining valued occupations**

#### Key Questions

**I'd like you to close your eyes and think for a moment about what it's like to have ataxia; ...if you met someone who knew very little/nothing about ataxia think about how would you describe what living with ataxia is like.**

**OK I'd like you to open your eyes and describe what it's like to live with ataxia.**

Probes:

Does anyone have anything else to add to the picture?

Has ataxia affected your relationships with other people?

How about things like aims, hopes, ambitions

**Can you describe (in more detail) how ataxia has affected your day to day activities?**

Probes e.g. the way you like to spend your time, the things you feel you like doing, your role at home or at work, the things that you feel are important for you to do?

Probe: Could you tell us about any day to day activities that give you particular satisfaction?

**Have you needed to change the way you do these things because of ataxia? If so, in what ways?**

Probe: Has anything that you've learnt or done been particularly useful in being able to continue with these activities?

**Have you taken up any new roles or activities?**

Probe: Have any other groups or organisations or people been helpful or unhelpful in supporting you doing the things that are important to you?

**Transition: We're now going to move on from activities in your daily life that are important to you to your physical activity and physiotherapy.**

**Topic: Experiences of physiotherapy (interventions and service provision)**

**What is the first thing that comes to mind when you hear the word physiotherapy? As opposed to personal trainer???)**

**(? Show of hands – who's had physiotherapy?)**

**So how would you define/describe physiotherapy?**

**Transition**

**Tell us about the process of being referred to a physiotherapist – (was this straight forward?)**

Probe: Could you tell us about how physiotherapy has been provided, for example do you get to see a physiotherapist very often?

Probe: Do you think there are barriers to receiving adequate physiotherapy?

**Key Questions**

**Theme: Contemporary practice**

**Could you describe the kinds of things you have done in physiotherapy?**

**Has physiotherapy been helpful?** (Probes: have you noticed changes in your physical ability (physical), ability to do the things or activities that interest you most (occupational), what about other benefits, how you feel about yourself or in yourself? (psychological))

**Did anything about physiotherapy surprise you?**

**What is most supportive about physiotherapy?**

**Could you tell us about any other sort exercise that you've found helpful? (Gym, stretches, swimming)**

**Is there anything about living with ataxia that stops you exercising or participating in activities that are important to you?**

**Ending Question:**

If you had a chance to give advice to physiotherapists about the most important things to consider when working with someone with ataxia what would it be?

**Ending Question:**

We would like this study to reflect your experience of living with ataxia and your experiences of physiotherapy. Is there anything that we've missed? Is there anything that you came wanting to say that you didn't get a chance to say?

**Summary**

Before bringing the group to a close, the researcher will summarise the key points made during the group and check with the group that these were captured accurately. Refreshments will be available and breaks taken at a convenient time during the discussion.

## **Appendix H: Lone Working Procedures**

1. Researcher to give name, address and contact details of participant to supervisor in a sealed envelope.
2. Inform supervisor of date and time of the interview.
3. Arrange to contact supervisor at a specified time +/- 30 minutes to confirm safe exit.
4. If no contact, supervisor to contact researcher via mobile phone.
5. If researcher does not respond, supervisor to open envelope and contact research participant.
6. If no further response, contact researcher's next of kin +/- appropriate authorities.
7. If no problems encountered, supervisor to confidentially dispose of unopened envelope.

## Appendix I

### Extract from Hugh's transcript to demonstrate improved interview technique

Hugh With me it came on with the accident. It seemed to affect my eyesight. When I was going shopping or walking down the aisle I couldn't focus on anything. It was giving me headaches, I just couldn't focus, I was driving a car still, and anything to the left or the right when I was driving I couldn't ... I can focus on things ahead, but when I first had the accident I could not focus on anything to the left or right.

I Right.

Hugh That improved quite a bit since the accident. I still find it harder focussing on things when I'm moving. The other thing with ataxia with my eyesight I can't judge ... when I'm walking, I can't see things in 3D. I don't know how big a step is, up or down. On uneven ground I can't see the bumps or the hollows, so I tend to trip quite a bit. It's also been affecting my walking and I don't know if it's the accident or ataxia. But when I move my legs ... not even, one leg's going higher than the other one which is part of the ataxia, by the time your brain sends a signal back to your leg to put its foot down, your leg's up to your chest sort of thing. So it affects you that way. Or sometimes when I'm really bad and I'm trying to pick things up I can't judge how far away they are and I miss them. When I'm typing on the computer it works sometimes, but got to be fairly careful, I hit or miss a key totally. Or I hit two keys, so you've got to be very careful on that. These days the computer can put it right. But 20 years ago or 30 years ago the computers (inaudible)

I Yeah.

Hugh So you can get round it. But that's part of the problem, my balance and walking gone off quite a bit now, I find it really difficult to get up out of the chair and walking around, the last year or so I can only walk along the wall or if I'm pushing a trolley or something to hold onto which stops me from falling over, something that's heavy. I cut the grass on the lawn by holding on tight to the lawnmower.

I You have what tied to the lawnmower?

Hugh By holding on tight to the lawnmower.

I Okay yeah.

Hugh That way. Sort of like I know where the ground is, and sort of like acts as a counterbalance.

I Yeah.

Hugh But when I first have trouble walking was with a walking stick. (inaudible) walking stick, I couldn't judge the distance to the ground but by using a stick that would tell me where the ground was.

I Ah okay.

Hugh I could get the information back to my brain

I Yeah.

Hugh That way was helpful. That helped quite a bit with ataxia with a stick it was easy but cos one of the side effects is doing two things at the same time, so you're trying to walk and put your stick down, it's very difficult sort of thing. So sometimes it helps and sometimes it gets in the way.

I Right okay. So sometimes a stick does act as a feedback to let you know where the ground is.

Hugh Yeah.

I And sometimes ...

Hugh Sometimes just by concentrating on the stick you can't think of two things. So you're trying to walk at the same time.

I Yeah.

Hugh You can't do it.

I No you can't do it.

Hugh Trying to keep the smooth walking, you can do it but you can't do it fast, you can't do it smoothly.

Hugh Yeah.

I So some days it's good, some days bad.

Hugh Yes. The other thing I found is ... I like photography, I've got quite a few cameras. If I put a camera round my neck and it's swinging that's totally ... my body can't handle it any more. So I can't carry the thing. I can't put a camera round my neck, the swaying ... my brain's reacting to it and I end up falling over, I can't walk even walk straight.

I So if the camera's swinging.

Hugh Swinging yeah. The balance with my brain trying to walk, the counterbalance.

I Right. Oh counterbalancing the swing of the camera, it's too difficult. Yeah okay.

Hugh So I've found it very very difficult. I can't carry a cup (inaudible) my tea. I've now got a cup with a lid on so ...

I Right.

Hugh ... so that helps. I've got thermal cups go quite tightly down. (?) What I have found that worked before thermal cups came on, I used to make a flask of tea, put the lid on and then carry that round and help myself. That way it wouldn't spill it but I can't carry anything without spilling it.

I Uhuh.

Hugh Because I get tired now I can't do ... I used to go swimming, I can't do that now because of coordination, with my legs and my arms, it's totally wrong, and I get very tired so ...

I You get tired with the swimming.

Hugh If I do a length or two that's me shattered.

I Right okay.

Hugh When I go walking ... it's got progressively worse in the last few years, it's got harder and harder walking. And it takes me longer and longer to recover so if I do too much it takes me longer to recover. I used to do a lot of training, like I kept myself fit. In the last few months I've reduced that as well.

I Just in the last few months?

Hugh Yeah it seems to be making me more and more tired so I cut down. I've got some weights so I do a bit of that but even that I seem to ... don't know what it is, motivation gone, it seems ... too much like ... like getting in from work, I'm so tired, I just want to sit down. Some days I'm good, some days I'm bad. It's hard, it's really hard.

I Yeah. And you're working now then?

Hugh I'm working ... I have been working 4 days a week. I had a meeting a couple of weeks back, I was supposed to start working from home, so that will have ... cos it takes me virtually an hour and virtually an hour to get back ... or more than an hour to get back.

I Right. And how do you get to and from work?

Hugh I'm still driving.

I You're still driving, okay.

Hugh And I drive a manual car, and they've agreed to change to an automatic ... we're getting a new car, automatic.

I Yeah.

Hugh So I manage to do that. My driving, I'm not as good as ... some people are better than others, but I drive well within my capability. When I was younger I used to drive everywhere I don't do it any more.

I No no.

Hugh Drive pretty careful. Take my time.

I Yeah. And so now you're going to start working from home more?

Hugh Yeah. We agreed that at beginning of next month I'll start working at home. But I've got 2 weeks holiday at the end of next month so I'll probably start next month so September so I'll probably leave ... get a few things out of the way at work, a

few jobs, so I'll get them out of the way. So I think it's probably too quick notice to

I Sure.

Hugh To react to it early. They agreed to it, but I think it's probably better for all of us if I wind down slowly at work and do it from home

I Yeah. Over the next month.

Hugh Yeah. Plus the children are off this month, so it's probably better next month.

I To start off. And so will that mean that you'll be permanently at home? You won't have to go into the office?

Hugh Well I'll go in one day a week.

## Appendix J: Developing super-ordinate themes a case example

The aim of this appendix is to provide a detailed account of data analysis to illustrate (as far as is practicable) how the analysis was carried out in the present study. A section from Jim's account has been used as a case example. This section focuses on the emergence of stigma in the account.

### Stage 1: a small section of the first stage of analysis from the interview with Jim

	Transcript
<i>Initial thoughts:</i>	
<i>Constant readjustment to disability; stick, wheelchair; never complete, stable</i>	Jim I should use a walking stick. I've got one in my bag, but I'm still coming to terms myself with the fact that I need to use it, <u>being seen</u> to be using it ... which is more about my own preconceptions and image I suppose. And I'm aware I guess longer term ... if it does get worse you could end up in a wheelchair but it's just something personally I find it very difficult to consider. I'd rather sort of stumble along and fall down.
<i>Next challenge – using a stick, fear wheelchair</i>	I Right. So what is it about the walking stick that you think that says about you?
<i>Adjustment 'coming to terms with' using a stick</i>	Jim I think it did just ... you're <u>self-conscious</u> anyway, which can create its own problems ... but having something <u>so obvious</u> as a walking stick, it's just a <u>visible</u> sign to everybody – yes I am definitely different.
<i>Being seen with a stick is bad – why – signal difference, self-conscious</i>	I Yeah.
<i>visible, obvious</i>	

Page 14, lines 37-50, I: interviewer, underlining was carried out by the researcher during analysis

#### Commentary

The left hand margin illustrates the initial thoughts of the researcher during the first phase of data analysis of Jim's account. The idea of an on-going readjustment to emerging or deteriorating impairments or the consequences of these impairments was developing and resonated with earlier parts of the transcript. The beginnings of an interpretation were emerging that for Jim meant that adjustment was never complete and that the next stage is always anticipated, the fear about "ending up" in a wheelchair. The analysis also demonstrates the beginnings of an understanding of the possible psychological issues connected to using a stick but the comments in the left hand paragraph do not move beyond noting the visibility Jim associates with using a stick.

## Second Phase Data Analysis (Jim)

### Commentary

The comments in the right-hand margin are at a higher level of abstraction. At this stage the comments are quite hesitant and provisional. The emerging themes seem to be concerned with the experience of stigma as well as thoughts about a feared future. The introduction of a walking stick seems to act as a catalyst; it alerts Jim to the threat of ataxia to his sense of self and reminds him of the way in which adjustments to disability have to be frequently revisited and incorporated into an acceptable way of being-in-the-world.

- Jim I should use a walking stick. I've got one in my bag, but I'm still coming to terms myself with the fact that I need to use it, being seen to be using it ... which is more about my own preconceptions and image I suppose. And I'm aware I guess longer term ... if it does get worse you could end up in a wheelchair but it's just something personally I find it very difficult to consider. I'd rather sort of stumble along and fall down.
- I Right. So what is it about the walking stick that you think that says about you?
- Jim I think it did just ... you're self-conscious anyway, which can create its own problems ... but having something so obvious as a walking stick, it's just a visible sign to everybody – yes I am definitely different.
- I Yeah.

Emerging themes:

Adjustment, dynamic process - projecting into a feared future?  
'You' not 'I' here and then back to 'I' – displacement, incongruence?

Wheelchair; final incapacity – rather stumble and fall than be in a wheelchair? Fear of what he might become?

Being seen with a stick is bad; diminishing? Stigma?

Why does he think he should use a stick? Who says so - common sense? He seems quite conflicted?

Transcript 11; page 14, Page 14, lines 37-50, I: interviewer, underlining = researcher during analysis

## **Provisional Super-ordinate Themes (*n* = 10)**

These themes were developed from firstly collecting all the possible themes from the right hand margin in the order they emerged in the interview and then clustering common topics together. Page and line numbers indicated.

### **Background information, signs and symptoms**

1:3	Background information son at University
1:12-20	Background information, age type of ataxia
2:35-50	Background; type of ataxia and genetics
3:1-2	Background continued; type of ataxia and genetics
3:27	Background, brother and sister have ataxia
14:5-16	Physical difficulties, balance, co-ordination, walking
13:10-15	Speech
15:33-43	Symptoms, sensory only participant to describe sensory symptoms
19:27-44	Fatigue, underlying, poorly treated medically
20:1-7	Fatigue

### **Missionary Zeal**

1:24-20	Mission: increase knowledge of ataxia, fuelled by experience of ignorance, help others; one of his 'fervent beliefs'
2:1	Mission: 'help others [...] that's part of the reason I exist'
2:11-12	Mission: 'I made a conscious decision' to help with research
2:16-35	Mission: help self; develop own expertise and understanding
3:7-9	Mission help children; natural or reinforced by ataxia
3:14	Mission: just to help everybody
3:18-19	Mission: consciousness raising

### **Jim's personal philosophy**

2:46-50	Philosophy: links to his mission; informed decision making
3:20-32	Philosophy; bringing the children up knowing about the ataxia
3:11-12	Motivations; 'guilty social conscience'
4:14-17	Positivity; bringing children up with ataxia, any bad times?
5:31-32	Philosophy changes, learn from other people, peer support?
5:39-40	Philosophy; positive mentality
5:48-49	Philosophy; getting a sense of perspective – over time
6:1-6	Journey, philosophy
6:7-9	Philosophy: live for the moment (he wouldn't be like this without the ataxia, almost his life is richer because of the ataxia, he hasn't said that but is that what is leaking through?) Perhaps this is because he has been diagnosed from an early age, compared to some of the other participants and he has been through the struggle etc with decades in front of him.
7:31-34	Philosophy; positive, 'see the light'
8:42-43	Better person, ataxia has made him a better person?
9:5-12	Consequences of defining moments, being more open
9:16-17	Consequences of defining moment open not angry
9:19-20	Consequences; spreading the word, what disability means, not what ataxia is, significant demarcation?
9:19-42	Spreading the word at work
10:1-4	Becoming an activist or becoming active, open
10:14	Being active; sky dive
10:18-19	Being active; set up a support group, why pushy parent link?

6:6-7	Philosophy; pushy parent
6:13-19	Pushy parent
6:21-30	Pushy parent, son rugby – why his son particularly?
6:34-35	Pushy parent – why. Exploit the opportunities he never had, having experienced loss he is aware that his children may experience similar losses, especially his son. He pushed him into rugby (a sport he liked but preferred cricket) knowing that he may experience the same loss, better to have lived and lost than to have never lived at all? Paradox? Does he also have regrets about what he didn't do when he was young, did nobody push him? Ataxia was in the family, but perhaps not understood in those terms.
7:18-25	Pushy parent, sport, gender differences
7:26-31	Pushy parent; going to extremes (financial extremes, physical extremes)

### **Rough Weather**

2:34-35	Ups and downs, not all rosie 'I just felt better in myself because...'
4:44-46	Anger, fight, negativity (initially all aspects of life but telling work a major milestone, bump)
10:26-27	Negative /inking into the on-going negatives 'shows I'm not alone'; alone in what not having the condition surely, but in feeling and behaving in the way he does?
10:29-31	Negative leaking through here? Does he still feel alone? Is the positivity fragile?
16:22-37	Meaningful occupation; humour. Jim's meaningful occupations have changed he no longer does sport but he does lots of other meaningful activities. Also though 'mentally accepting it' is an on-going issue.
10:31-34	Negative; can he see himself in this young girl, scared?
11:3-4	Regrets? The sooner you accept the better?
5:16-17	Journey; coming full circle re work
5:19-32	Journey; moving from one perspective to another
11:13-14	Negative; fragile confidence and new found strength, would be lost without his wife's support; she's sort of a silent resource, rock throughout the account.
11:16-18	Hint at past experience of not being open within the family?
11:22-27	Motivation help others see the positives, is he saying that his life is richer than without the ataxia?
11:33-39	Aware of the negative side of his current thinking; passionate, carried away, fanatical enthusiasm, hearty persistent endeavour, intense.
12:1	Totally relaxed with it – his ataxia or his new found enthusiasms?
12:17-25	Zealot; achieving balance with the new understanding of his condition? Meaning, sense making???

### **Biographical Disruption**

4:23-44	Biographical disruption, anger, loss, difference
5:1-15	Anger, loss of trust, loss, difference (felt acutely at work)
7:1-17	Loss, ongoing losses, compromise, loss; biographical disruption. Not associated with age, other participants. Is the shock here more acute because of his age, or is this biographical disruption the same however long you've lived.

12:31-35	Development of symptoms, physical signs; disbelief, denial
13:1-3	Denial
13:3-9	Trauma - giving up sport, generally in this section 'little deaths'

### **Revelations and defining moments**

7:38-43	Trigger, defining moment, course at work: be positive
8:1-2	Trigger, defining moment, course at work: be positive
8:3-42	Trigger, defining moment, understanding difference from another perspective
8:48-49	Defining moments – his description (compare to 7:39-41)

### **Ataxia in and within the Family**

6:14	Wife supportive, she would have known about the ataxia when they got married
16:11-37	Guilt, adaptation to dependency
11:5-7	Strong family involvement, son co-ordinator of group
4:1-9	Daughter has become politicised
11:13-14	Negative; fragile confidence and new found strength, would be lost without his wife's support; she's sort of a silent resource, rock throughout the account.

### **Hegemony: fighting the good fight**

13:10-15	Speech beating my self up about it
13:15-27	Speech – experience of speech and language therapy
13:22-46	Key bit of text about needing permission to 'give up' the pressure to fight not accept, to conform to beliefs of others about the valiant fight.
14:1-5	Speech, continued
17:3-27	Exercise; went a bit mad; attitude to most things, go at it full on? Or obliged to be seen to fight the good fight? Attitude to exercise now changed? See below.
17:34-42	Exercise; calf muscles stronger, also confidence.
18:3-16	Exercise; feel good, perhaps underestimated by other e.g. HCPs

### **Hegemony and Stigma**

14:5-16	Stigma Physical difficulties, balance, co-ordination, walking
14:16-35	Stigma, 'the stare'
14:37-44	Concerns about the future, look at the language I/you
14:37-48	Stigma, the stare, still coping with it, not wanting to be different, internalised hegemony but also practical problems p15
15:1-2	Stigma/hegemony 'I'm different', want to be like everyone else.
15:4-9	Stigma but also practical problems using a stick
15:14-16	Stigma – prefer to hold wife's hand; look less out of place, avoid the stare
15:18-21	Stigma stick practical problems.
5:1-15	Anger, loss of trust, loss, difference (felt acutely at work)

### **Frustration with HPC**

He came to his epiphany (sudden and important manifestation or realisation) without the help of HPCs, although it wasn't sudden.

18:20-44	Physiotherapy; frustration
19:1-8	Physiotherapy; frustrating (20 years ago)

19:12-23	Physiotherapy; ambivalent?
15:24-33	Frustrated with other HPCs for different reasons, pigeon holed, cerebellar ataxia accounts for all other health problems e.g. restless leg syndrome

At this stage, a narrative account was written for each of the provisional super-ordinate themes identified in Jim's account. The following extract from Jim's narrative account (Box 1) shows how each super-ordinate theme was written up in the first instance as part of the case by case analysis. The section is taken from a larger part of the narrative account under the super-ordinate theme of 'Hegemony and Stigma'.

### Box 1. Extract from the narrative summary of Jim's super-ordinate themes

**Jim described how he coped with stigma and the effect of those experiences in the following extract;**

14:16-35 'It isn't a problem for me, but I'm aware that other people because of their preconceived ideas about it probably think 'Christ, he's had too much to drink' or 'What is he doing?' Which again I try to look on the positive side, what people think doesn't affect me. But it does make me very upset and slightly angry when you're with your family, because people do make hurtful comments. You can see people's eyes just burning holes through your back. But again I've learnt to deal with it and you become hard skinned and hard nosed ... but for my wife and for my kids it's sometimes difficult to accept. Although they do, so you feel ... not guilty, you just get upset because of what they could be thinking. So me at work um ... part of my job involves working in big offices, going to contact centres, and when you walk about there or when you're talking to somebody you can realise very simply there are loads of pairs of eyes going chu-chu-chu – looking at you and thinking 'What's wrong with him?' I think that is probably the biggest problem that anybody with I suppose any disability has coming to terms with it, accepting that you are different.'

**In the above extract Jim describes an ongoing battle to choose what he gives meaning to; he feels the 'stare' and therefore the continual reminder of being different; 'people's eyes just burning holes through your back' and 'there are loads of pairs of eyes going chu-chu-chu – looking at you and thinking 'What's wrong with him?' but he tries to be positive, he makes a decision not to be affected by these transgressions of his personal space and what they mean; 'what people think doesn't affect me'. But his ability to exercise choice and exert control in his life is always under threat; 'I think that is probably the biggest problem that anybody with I suppose any disability has coming to terms with it, accepting that you are different.' From an existential perspective Jim attempts to choose what he gives meaning to, he is trying to escape feeling different by choosing not to be affected by what people think but as in other conditions the stigma of the stare is a continual reminder of 'deviance' (Whalley Hammell, 2006). Also, although he can try to exert a choice over what he gives meaning to, he is unable to choose what his family pay attention to therefore he feels upset and angry about comments or being stared at in public when his family are with him. He describes being 'upset because of what they [his family] could be thinking'. The meaning of this phrase is not completely clear because Jim does not go into any more detail however, he might be thinking that his family are upset by the comments or he might also be concerned that his children are thinking that one day they might have to deal with the same degree of stigma. It must be painful to think about exposing his family to something that he cannot control for them but they experience only as a consequence of his disability.**

At this stage, the analysis remained provisional and unfolding and only parts of the original list of themes were retained in the overall master super-ordinate themes of the study. Confidence was developed through working with the data, the interpretation shifted as new questions emerged, and as a result the original text was re-visited and re-evaluated many times. This approach is consistent with the iterative stance and is an accepted component of IPA (Smith et al, 2009). As part of the pruning process, themes which did not work well to illuminate the phenomenon were reconsidered, reconstructed or subsumed within another superordinate theme. Overall five superordinate themes were developed from Jim's account. Table 1 indicates the pruned superordinate themes and subthemes. However, the overall themes were only finalised following further analytic work during the cross case analyses and writing up.

**Table 1 Development of Superordinate Themes and Subthemes for Jim**

<b>Superordinate Theme (n = 5)</b> Subthemes	<b>Page/line number</b>	<b>Key quotation</b>
<b><i>Ataxia in and within the family</i></b> Presence in the family Comfortable at home	3:22 4:16	<i>'Basically been brought up with it'</i> <i>'They don't see it as a problem'</i>
<b><i>Getting back on track / taking control</i></b> Changing perspectives Affirming a sense of self	5:32 1:29	<i>'Disability isn't your problem'</i> <i>'If I can help others [...] that's part of the reason I exist'</i>
<b><i>Stigma</i></b> Difference and unwanted attention Rejection of stigma symbols	14:31 14:48	<i>'Loads of pairs of eyes going chu-chu-chu'</i> <i>'Having something so obvious as a walking stick'</i>
<b><i>Lack of support at critical times</i></b> Thwarted and frustrated Left high and dry	19:3 7:9	<i>'There's just nothing we can do'</i> <i>'No support, no nothing'</i>
<b><i>Understanding and managing symptoms</i></b> Keeping physically fit Disordered movement Fatigue	17:38 14:12 19:36	<i>'You just feel better for doing something'</i> <i>'You look like you're drunk'</i> <i>'You do feel tired'</i>

Jim's original superordinate themes were preserved in the final list of master themes but renamed and redistributed as the researcher's thinking and familiarity with the data

deepened and changed in the process of conducting the cross case analysis and during writing up. Table 2 demonstrates how Jim’s themes were reconfigured.

**Table 2 Reconfiguration of Jim’s Superordinate Themes into the Master Superordinate Themes**

Jim’s superordinate themes		Master themes
<i>Ataxia in and within the family</i>		<i>The embodied experience of living with progressive cerebellar ataxia</i>
<i>Getting back on track / taking control</i>		<i>Identity, stigma and disrupted embodiment in public places and spaces</i>
<i>Stigma</i>		<i>Lifeworld meets biomedicine: a complex juxtaposition</i>
<i>Lack of support at critical times</i>		<i>Wresting control in the face of uncertain and changing forces</i>
<i>Understanding and managing symptoms</i>		<i>Exercise: a multi-faceted contributor to managing life with ataxia</i>

The individual superordinate and subthemes for each participant are presented in Appendix K.

## Appendix K

### Mapping Super-ordinate Themes for Each Participant into Master Super-ordinate Themes

Joan's super-ordinate themes		Master super-ordinate themes
<b>Struggle, fight and uncertainty</b> 1:24 'he thinks there's no such thing as ataxia wrong with me'		The embodied experience of living with progressive cerebellar ataxia
<b>Taking control and managing health</b> 4:1 'I'm managing 'it' the ataxia ... and how it behaves'		Identity, stigma and disrupted embodiment in public places and spaces
<b>Experience of physiotherapy</b> 12:42 'particular exercises all of which I wrote down, I can't remember'		Lifeworld meets biomedicine: a complex juxtaposition
<b>Symptoms</b> 2:39 'unable to co-ordinate my limbs together'		Wrestling control in the face of uncertain and changing forces
<b>Exercise is nourishing</b> 'with exercise the spirits are lifted' (post-interview phone call)		Exercise: a multi-faceted contributor to managing life with ataxia

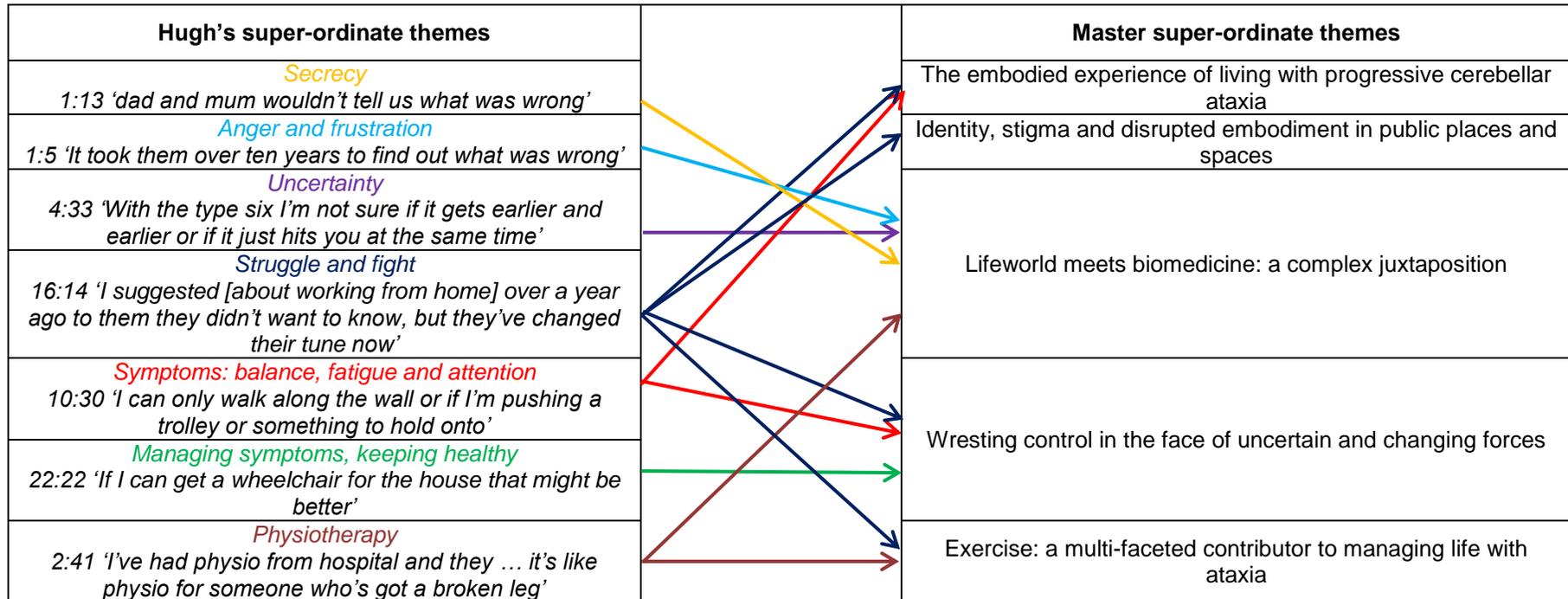
Stella's super-ordinate themes		Master super-ordinate themes
<b>Symptoms</b> 5:28 'my balance is poor and I can easily fall'		The embodied experience of living with progressive cerebellar ataxia
<b>Loss of self</b> 3:1-2 'I used to be so active I find it very hard'		Identity, stigma and disrupted embodiment in public places and spaces
<b>Uncertainty and fear</b> 3:4 'they can't diagnose which ataxia I've got'		Lifeworld meets biomedicine: a complex juxtaposition
<b>Abandonment and helplessness</b> 2:20 'you're floundering about in the dark and you haven't any contact'		Wrestling control in the face of uncertain and changing forces
<b>Fighting on and fighting back</b> 1:29 'I went back to my GP and got him to refer me'		Exercise: a multi-faceted contributor to managing life with ataxia
<b>Physiotherapy</b> 18:24 'they just don't have the staff I suppose, and the knowledge'		

Harry's super-ordinate themes		Master super-ordinate themes
<b>Symptoms</b> 9:28 'That's one thing you lose - your automatic bits'	→	The embodied experience of living with progressive cerebellar ataxia
<b>Taking blows</b> 3:35 'I loved riding mountain bikes and now I just couldn't'	→	Identity, stigma and disrupted embodiment in public places and spaces
<b>Fighting back: taking control and managing health</b> 5:21 'When you're out there nobody can see the wheelchair'	→	Lifeworld meets biomedicine: a complex juxtaposition
<b>Physiotherapy</b> 14:28 'You can't walk into a physio place and just go 'Fix me''	→	Wresting control in the face of uncertain and changing forces
	→	Exercise: a multi-faceted contributor to managing life with ataxia

Bill's super-ordinate themes		Master super-ordinate themes
<b>Symptoms</b> 4:27 'kind of like everything is uncoordinated'	→	The embodied experience of living with progressive cerebellar ataxia
<b>Loss</b> 6:18 'I feel in myself as it were, little bit inclined to be quiet'	→	Identity, stigma and disrupted embodiment in public places and spaces
<b>Limited information and poor communication</b> 3:3 'some information at that kind of level would be useful'	→	Lifeworld meets biomedicine: a complex juxtaposition
<b>Taking control: addressing issues</b> 14:10 'I wrote an article for the [newspaper] about ataxia'	→	Wresting control in the face of uncertain and changing forces
<b>Finding support</b> 8:38 'one of the people who calls who we've as it were befriended, got to know'	→	Exercise: a multi-faceted contributor to managing life with ataxia
<b>Physiotherapy</b> 1:7 'my experience has been one of the therapists saying 'Oh, never heard of it''	→	

Toby's super-ordinate themes		Master super-ordinate themes
<b>Symptoms</b> 5:19 'like my top half wasn't connected to my bottom half'	→	The embodied experience of living with progressive cerebellar ataxia
<b>Struggle and fight</b> 2:10 'that year, I went [to the GP] and I said 'This can't be normal''	→	Identity, stigma and disrupted embodiment in public places and spaces
<b>Taking control and managing health</b> 4:40 'I go swimming three times a week'	→	Lifeworld meets biomedicine: a complex juxtaposition
<b>Physiotherapy</b> 14:1 'physio gave me an open appointment so that if I needed to go I could ring'	→	Wresting control in the face of uncertain and changing forces
	→	Exercise: a multi-faceted contributor to managing life with ataxia

Julia's super-ordinate themes		Master super-ordinate themes
<b>Symptoms</b> 10:3 'It gets worse as I get more tired'	→	The embodied experience of living with progressive cerebellar ataxia
<b>Keeping control</b> 15:20 'If I wanted to stay independent I had to fight as long as I could'	→	Identity, stigma and disrupted embodiment in public places and spaces
<b>Shame and Stigma</b> 7:28 'I don't want to seem odd in public'	→	Lifeworld meets biomedicine: a complex juxtaposition
<b>Reconstructing identity</b> 1:18 'being part of research programmes makes me feel that I can still be useful'	→	Wresting control in the face of uncertain and changing forces
<b>Coping strategies and self-management</b> 1:22 'I learned that if I planned my movements I'm much more likely to succeed'	→	Exercise: a multi-faceted contributor to managing life with ataxia
<b>Exercise to maintain participation</b> 3:1 'the stairs ... if I can't do them then I won't be invited to baby-sit'	→	
<b>Valuing partnerships with physiotherapists</b> 18:14 'I do think that you need to go back every now and then just to be checked over'	→	



Susan's super-ordinate themes		Master super-ordinate themes
<b>Living with uncertainty: campaigning and persuading</b> 5:12 'I'm now trying to find out which type of ataxia I have'		The embodied experience of living with progressive cerebellar ataxia
<b>Surrendering and fighting on</b> 7:25 'I don't like to go into the social situation where I feel I'm being judged'		Identity, stigma and disrupted embodiment in public places and spaces
<b>Signs and symptoms: losing time, balance and concentration</b> 4:14 'I'm tired all the time it's just a way of life'		Lifeworld meets biomedicine: a complex juxtaposition
<b>Physiotherapy: good, bad and insufficient</b> 13:33 'I'm not so sure that she wasn't thinking more of a stroke victim'		Wresting control in the face of uncertain and changing forces
		Exercise: a multi-faceted contributor to managing life with ataxia

Scott's super-ordinate themes		Master super-ordinate themes
<b>Uncertainty</b> 16:25 'what I've now got ... which is still not diagnosed'		The embodied experience of living with progressive cerebellar ataxia
<b>Symptoms</b> 2:5 'my thought processes were completely disrupted as well'		Identity, stigma and disrupted embodiment in public places and spaces
<b>Struggle and disempowerment</b> 4:42 'very difficult to get people to understand what you're going through'		Lifeworld meets biomedicine: a complex juxtaposition
<b>Isolation and depression</b> 6:9 'You don't have a social life'		Wresting control in the face of uncertain and changing forces
<b>Fighting back and taking control</b> 10:17 'You've got to plan your day'		Wresting control in the face of uncertain and changing forces
<b>Shared experiences, collective voices</b> 18:12 'You're not on your own'		Wresting control in the face of uncertain and changing forces
<b>Physiotherapy</b> 14:24 'keep yourself lubed up with, something that's not going to be a bind'		Exercise: a multi-faceted contributor to managing life with ataxia

Graham's super-ordinate themes		Master super-ordinate themes
<b>Uncertainty</b> 17:20 'it's difficult for me to actually say what my illness is'		The embodied experience of living with progressive cerebellar ataxia
<b>Symptoms</b> 8:37 'I tend to sort of go too far or not quite far enough'		Identity, stigma and disrupted embodiment in public places and spaces
<b>Struggle and disempowerment</b> 15:47 'it doesn't feel like I'm getting much attention'		Lifeworld meets biomedicine: a complex juxtaposition
<b>Isolation and depression</b> 6:48 'you start turning things down'		Wresting control in the face of uncertain and changing forces
<b>Fighting back and taking control</b> 19:20 'to actually play it again even though I'm frustrated [...], it's much better'		
<b>Shared experiences, collective voices</b> 18:4 'if we all club together we've got more of a voice'		Exercise: a multi-faceted contributor to managing life with ataxia
<b>Physiotherapy</b> 13:37 'somebody else is actually taking a bit of interest, which I find as important as physical aspects'		

Ted's super-ordinate themes		Master super-ordinate themes
<b>Uncertainty</b> 10:1 'it was almost a relief to be told that you weren't just clumsy, there is a reason.'		The embodied experience of living with progressive cerebellar ataxia
		Identity, stigma and disrupted embodiment in public places and spaces
	Lifeworld meets biomedicine: a complex juxtaposition	
	Wresting control in the face of uncertain and changing forces	
<b>Physiotherapy</b> 8:28 'It makes me feel better that I'm actually doing something'	Exercise: a multi-faceted contributor to managing life with ataxia	

## **Appendix L Publications and Conference Presentations**

### **Publications**

Cassidy, E., Reynolds, F., Naylor, S. and De Souza L. (2011) Using interpretative phenomenological analysis to inform physiotherapy practice: an introduction with reference to the lived experience of cerebellar ataxia. *Physiotherapy Theory and Practice* 27 (4), pp. 263-277.

Cassidy, E., Reynolds, F., Naylor, S. and De Souza L. (2009) What is Interpretative Phenomenological Analysis and how might it inform physiotherapy practice in neurorehabilitation? An overview with reference to an analysis of the lived experience of ataxia. *Syn'apse*, pp5-10.

### **Conference Presentations**

Cassidy, E. (2011) Ataxia: Understanding the lived experience. SouthWest ACPIN study day, Bristol.

Cassidy, E. (2009) Understanding the lived experience of cerebellar ataxia. ACPIN study day, London.

Cassidy, E., Reynolds, F., Naylor, S. and De Souza, L. (2008) Fighting Back and Taking Control: People with Cerebellar Ataxia Reflect on the Role of Exercise in Coping with their Condition. Chartered Society of Physiotherapy Congress.

Cassidy E., Reynolds F., Naylor S., De Souza L. and Khan A. (2008) Shining a Light on Physiotherapy: the experiences of people with cerebellar ataxia. Proceedings of Society of Research in Rehabilitation, Abstract published in *Clinical Rehabilitation* (22), 860.

### **Other Presentations and Talks:**

Cassidy, E. (2010) The embodied experience of living with cerebellar ataxia: an interpretative phenomenological analysis. PhD student conference, SHSSC, BU.

Cassidy, E. (2010) Understanding Cerebellar Ataxia. Richmond and District Neurophysiotherapy Meeting (March 2010).

Cassidy, E (2008) Living with Ataxia: people with ataxia reflect on their experiences. National Hospital for Neurology and Neurosurgery, Queen Square, London. Joint Therapy Teaching. (August 2010)

Cassidy, E. (2008) Fighting Back and Taking Control: people with cerebellar ataxia reflect on the role of exercise in coping with their condition. Clayponds Rehabilitation Unit, Therapy Teaching (May 2008).

Cassidy, E. (2008) Fighting Back and Taking Control: people with cerebellar ataxia reflect on the role of exercise in coping with their condition. Charing Cross Hospital, Physiotherapy Teaching (May 2008).

Cassidy, E (2007) Living with ataxia: A phenomenological study. PhD student conference SHSSC, BU, (poster).

## Appendix M

### Overview of Svenaeus' (2000a, b, 2001, 2011) phenomenology of illness and Todres' and Galvin's (2010) existential theory of well-being

Svenaeus (2000a, b, 2001, 2011) drew primarily on Heidegger (1962 [1927]) to propose a phenomenological theory of illness as redolent of an unhomelike being-in-the-world. What follows is a short synopsis of Heideggerian philosophy germane to Svenaeus' proposals. The key concepts are explored and the meaning of homelike and unhomelike being-in-the-world is clarified. An explanation and critique of Svenaeus' phenomenology of illness as unhomelike being-in-the-world is then offered with explicit reference to the findings of the present study.

In *Being and Time* (1962 [1927]), Heidegger emphasised that human existence is characterised by engagement in the world. By this, Heidegger meant that our lives as human beings are grounded upon our implicit absorption in our activities and projects, and our involvements with other people. Furthermore, our world, the environment in which we find ourselves, is full of useful things that are meaningful to us and with which we become fascinated and occupied. We lose ourselves in this world and are 'tranquilized' by its comfortable familiarity (op. cit. 189/234). In this sense, the world is homey, cosy even (Critchley, 2009). However, by being bound up with the world and others in this way, our lives, the shape they take up, coalesce or homogenize with the mass of human existence and are defined by it. Heidegger explained; 'The "they" prescribes one's state-of-mind, and determines what and how one "sees"' (op. cit. 170/213). The "they" stands for a collective that 'suppresses everything unfamiliar' (op. cit. 192/237). By closing down the unknown and the untested "the they" effectively constrain the possibilities of a person's life (Gorner, 2007). Heidegger therefore argued that what he saw as our natural but myopic tendency to "follow the crowd", and to "do the done thing", our unquestioning immersion in the comfortable everydayness of life, is an inauthentic form of existence. This is because, in living this way, our lives are interpreted for us by the 'they-self' and this stifles any attempt to live as an individual: 'it is not I' (Heidegger, 1962 [1927]:129/167). By living a life ceded to others, a person may feel at home and at ease in the world, but this sort of existence is a 'sham' (op. cit. 178/223).

Heidegger (1962 [1927]) argued that Angst, or anxiety, pulls us back from our absorption in the world and reveals possibilities for living an authentic life. The sense of pulling back is important because our potential for living a different sort of life is normally

covered up by our inauthentic involvement in the world. Heidegger explained that 'in anxiety one feels *uncanny*', or 'unhomelike' (op. cit.189/233, original emphasis, and footnote 1, Macquarrie and Robinson, 1962). What was once comfortable and familiar now feels strange. Anxiety is therefore experienced as a particular attunement of human being that briefly exposes the fundamental unhomelikeness of existence, the banality of everyday life, its insignificance, and the inauthentic meaning we attach to living (Moran, 2000, Critchley, 2009). This fundamental not-at-homeness is ordinarily dimmed by absorption in and fascination with our projects and tasks, and the chatter and bustle of ordinary life.

It therefore takes an uncomfortable mood like Angst to reveal our life for what it is. Angst reveals that human existence has no meaning in itself. For Heidegger, unhomelikeness, revealed through anxiety, is at the heart of our existence but we do not grasp what we are anxious about in an intellectual way, by choosing to abstractly think about the nature of existence. The reason for this is that the subject of our anxiety is not an entity in the world. We are not anxious about some "thing" in the world but our existence as such (Gorner, 2007). Heidegger explained; 'Anxiety is anxious in the face of the "nothing" of the world' (Heidegger, 1927 [1962]:343/393). In other words, in the particular attunement of anxiety, our everyday life, as we normally understand it, is revealed as holding no meaning in and of itself. By understanding that our existence, and the meaning we attach to it, is based on nothing, we are seized by the meaninglessness of our lives and, by doing so, we become momentarily self-aware. It is in this instant that we distinguish ourselves from the world and from others, and realise the potential for our future existence (Gorner, 2007). Heidegger (1962 [1927]:343/393) suggested that, in this moment, the world and the things that we value sink into insignificance: 'Anxiety discloses an insignificance of the world; and this insignificance reveals the nullity'. This feels uncomfortable and disrupts our sense of belonging in our everyday life. It is as if all the things and people with which we are interested and involved disappear down a plug hole and drain away. This emptying out of things and others discloses us as naked and alone, as individuals, free to choose, as well as to reject, possibilities for our continuing lives (Critchley, 2009). For Heidegger (1962 [1927]:345/395), this sense of not-being-at-home, this existential homelessness, revealed through a mood of anxiety or Angst, works like a "wake up call" that liberates us from comfortable but inauthentic lives that 'count for nothing'. This awakening opens up other possibilities for living that offer an authentic mode of existence.

Using the arguments outlined above, Svenaeus (2000a, b, 2001) proposed that if unhomelike being-in-the world is fundamental to the human condition but generally hidden, then illness may also reveal this latent state. For Svenaeus (2001), health should be understood as a being-at-home that keeps the unfamiliarity of the not-being-at-home at bay. Illness, by contrast, is like a tidal wave that carries the uncanny into our otherwise numbing but homelike existence: 'the basic alienness of my being-in-the-world, which in health is always receding into the background, breaks forth in illness to pervade existence' (op. cit. 93). In illness, Svenaeus (2000a) argues, our lives become incomprehensible and incoherent. These uncomfortable feelings press in on us to the extent that the meaning and significance of everyday life blurs and falls away. Put simply, life can turn uncanny in illness. We do not need to be assailed by an anxious mood in order to understand the basic unhomelikeness of our existence in the world. By suggesting that unhomelikeness can be revealed by illness (some "thing" in the world) 'which in turn might let loose feelings and thoughts on the ultimate meaning of life' (op. cit. 11), Svenaeus inverts Heidegger's original conceit. However, he admits that this reading of Heidegger is unorthodox, and proposed it as an alternative view 'to inspire empirical challenge and confirmation' (Svenaeus, 2000a:4).

Svenaeus (2000a, b, 2001, 2011) set out to produce a philosophical explication or a general theory of the essence of illness based on a reading of Heidegger's *Being and Time*. Drawing on imaginary or adapted accounts of illness experience (e.g. diabetes and stroke), as well as phenomenological accounts of the body in health and illness (e.g. Zaner, 1981), and examples of particular illnesses such as MS (Toombs, 1992) and chronic pain (e.g. Leder, 1990), Svenaeus put forward a hypothesis that in illness 'the lived body takes on alien qualities' (2011:333). The otherness of the ill body, the loss of mastery and the changes in outward appearance that accompany illness were used to support this argument, and to further his contention that ill health is experienced as an unhomelike being in the world. Furthermore, with reference to biography (e.g. Frank, 1997), fictional writing and case studies, Svenaeus suggested that in ill health the present becomes the focus of the person's world such that the temporal structure of illness can be 'conceptualised as an *alienation* of past and future' (Svenaeus, 2011:339, original emphasis).

In his later work, Heidegger (1973 [1969]:5/11) ventured that it was possible to 'grant a dwelling for man in the midst of things'. In other words, he raised the possibility of homecoming within homelessness. Mugerauer (2008) explained that Heidegger's later philosophy made it possible to feel strange and unhomelike, without being overwhelmed

by it or fleeing in the face of it. Building on Svenaeus' (2001) work and guided by Mugerauer's (2008) interpretation of Heidegger's later philosophy (e.g. 1966 [1955]; 1973 [1969]; 1993 [1971]; 2001), Todres and Galvin (2010) and Galvin and Todres (2011) focussed on how the phenomenon of existential homelessness, as experienced in illness, could be reframed to incorporate the possibility of existential homecoming. These authors suggested that the unhomelike qualities of illness experience could be overcome, or at least modified, by promoting well-being. In other words, that there were ways of feeling comfortable and existentially "at home" (even if only for moments at a time) whilst simultaneously experiencing the discomfort of unhomelike being-in-the-world.

Heidegger (1966 [1955]) offered two interconnected ways by which it was possible to accommodate unhomelikeness, firstly through a kind of dwelling and secondly via a kind of mobility. He argued that in contrast to homelessness, homecoming understood as dwelling, is possible when we accept what is, when we stay engaged with what is felt as strange and unhomelike without drowning, or forgetting that it is possible to be otherwise (Mugerauer, 2008). At the same time, dwelling also means staying connected with the past and preserving its continuity, when the 'remnants of historical tradition remain together', when we hold onto the parts of our lives that are meaningful (Mugerauer, 2008:486). Homecoming, understood as mobility, is possible when we generate new modes of belonging. These modes may be discontinuous with the past or what might have been expected, but nonetheless maintain the sense that we are in some way "still underway" or "in the making" (Mugerauer, 2008). Homecoming through mobility might be better understood as happening when we take on new projects, tasks or roles; when we engage in things that contribute to constructing a sense of identity that is always moving forward. Heidegger described dwelling and mobility as a 'comportment [...] which expresses 'yes' and at the same time 'no' (Heidegger, 1966 [1955]:54-55). Put differently, the discomfort of our fundamentally unhomelike existence is let in and acknowledged but it does not hold sway, dominate or tranquilize (Mugerauer, 2008).

## Appendix N

### Prevalence of participants in each theme organised with respect to gender

Participant	Super-ordinate Theme 1 Embodiment (n=12)			Super-ordinate Theme 2 Stigma (n=8)				Super-ordinate Theme 3 Biomedicine (n=12)		Super-ordinate Theme 4 Control (n=11)			Super-ordinate Theme 5 Exercise (n=12)		Total n=14
	Subthemes (3)			Subthemes (4)				Subthemes (2)		Subthemes (3)			Subthemes (2)		
Bill	✓			✓				✓		✓			✓		8
	✓			✓				✓	✓	✓	✓	✓		✓	
Hugh	✓			✓				✓		✓			✓		9
	✓	✓	✓			✓		✓	✓	✓	✓			✓	
Harry	✓			✓				✓		✓			✓		12
	✓	✓	✓	✓	✓	✓		✓	✓		✓	✓	✓	✓	
Ted	✓							✓					✓		4
	✓		✓					✓					✓		
Scott	✓							✓		✓			✓		10
	✓	✓	✓					✓	✓	✓	✓	✓	✓	✓	
Toby	✓			✓				✓		✓			✓		10
	✓	✓	✓	✓		✓		✓	✓		✓		✓	✓	
Jim	✓			✓				✓		✓			✓		9
	✓			✓	✓	✓			✓	✓	✓		✓	✓	
Graham	✓							✓		✓			✓		10
	✓	✓	✓					✓	✓	✓	✓	✓	✓	✓	
Julia	✓			✓				✓		✓			✓		11
	✓	✓	✓	✓			✓	✓	✓		✓	✓	✓	✓	
Joan	✓							✓		✓			✓		8
	✓	✓	✓					✓	✓		✓	✓	✓		
Susan	✓			✓				✓		✓			✓		11
	✓	✓	✓	✓			✓	✓	✓	✓	✓			✓	
Stella	✓			✓				✓		✓			✓		9
	✓	✓		✓	✓			✓	✓	✓	✓			✓	

Participant (ascending order of age)	Super-ordinate Theme 1 Embodiment (n=12)			Super-ordinate Theme 2 Stigma (n=8)				Super-ordinate Theme 3 Biomedicine (n=12)		Super-ordinate Theme 4 Control (n=11)			Super-ordinate Theme 5 Exercise (n=12)		Total n=14
	Subthemes (3)			Subthemes (4)				Subthemes (2)		Subthemes (3)			Subthemes (2)		
Harry 30s	✓			✓				✓		✓			✓		12
	✓	✓	✓	✓	✓	✓		✓	✓		✓	✓	✓	✓	
Ted 40s	✓							✓					✓		4
	✓		✓					✓					✓		
Scott 40s	✓							✓		✓			✓		10
	✓	✓	✓					✓	✓	✓	✓	✓	✓	✓	
Jim 40s	✓			✓				✓		✓			✓		9
	✓			✓	✓	✓			✓	✓	✓		✓	✓	
Graham 40s	✓							✓		✓			✓		10
	✓	✓	✓					✓	✓	✓	✓	✓	✓	✓	
Toby 50s	✓			✓				✓		✓			✓		10
	✓	✓	✓	✓		✓		✓	✓		✓		✓	✓	
Hugh 50s	✓			✓				✓		✓			✓		9
	✓	✓	✓			✓		✓	✓	✓	✓			✓	
Bill 50s	✓			✓				✓		✓			✓		8
	✓			✓				✓	✓	✓	✓	✓		✓	
Stella 50s	✓			✓				✓		✓			✓		9
	✓	✓		✓	✓			✓	✓	✓	✓			✓	
Julia 60s	✓			✓				✓		✓			✓		11
	✓	✓	✓	✓			✓	✓	✓		✓	✓	✓	✓	
Susan 60s	✓			✓				✓		✓			✓		11
	✓	✓	✓	✓			✓	✓	✓	✓	✓	✓		✓	
Joan 70s	✓							✓		✓			✓		8
	✓	✓	✓					✓	✓		✓	✓	✓		

**Key:** Grey box refers to super-ordinate theme, ✓ = theme present in the account  
Blue box refers to sub-themes, ✓ = theme present in the account

**Prevalence of participants in each theme organised with respect to age**