

ABSTRACT

Qualitative research methods that focus on the lived experience of people with health conditions are relatively underutilised in physiotherapy research. This paper aims to introduce Interpretative Phenomenological Analysis (IPA), a research methodology oriented towards exploring and understanding the experience of a particular phenomenon e.g. living with spinal cord injury or chronic pain, or being the carer of someone with a particular health condition. Researchers using IPA try to find out how people make sense of their experiences and the meanings they attach to them. The findings from IPA research are highly nuanced and offer a fine grained understanding 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. We advocate IPA as a useful and accessible approach to qualitative research that can be used in the clinical setting to inform physiotherapy practice and the development of services from the perspective of individuals with particular health conditions.

INTRODUCTION

One aim of qualitative health research is to provide a multidimensional understanding of a person's experience of a health condition that goes beyond an everyday or common sense awareness and which leads to a more informed, nuanced and empathic practice (Curry, Nembhard and Bradley, 2009; Kearney, 2001; Mattingly, 1993; Shepard et al, 1993). This sort of qualitative enquiry has attracted little attention from physiotherapy researchers (Rauscher and Greenfield, 2009). This paper introduces Interpretative Phenomenological Analysis (IPA) as an approach to qualitative research and aims to demonstrate how it can help clinicians understand patients' experiences and how the findings might be used to inform physiotherapy practice. This is the first time that IPA, as a specific type of phenomenological

research, has been introduced in an international journal whose readership consists primarily of physiotherapists.

Dean, Smith and Payne (2006:140) recommended IPA for physiotherapy researchers because of its 'practical' orientation. A number of authors, who are experienced in IPA research, have produced clear and readily accessible guidelines and step-by-step introductions to data collection and analysis which may be particularly helpful for the novice, as well as the more experienced researcher using IPA for the first time. IPA can be undertaken in the clinical setting, within any specialty and it can be used to examine questions of cross disciplinary interest, independently or in combination with quantitative methods. Furthermore IPA can be used as part of collaborative research projects that are compatible with national funding strategies (see for example the UK based Research for Patient Benefit Programme, National Institute for Health Research, 2008). For researchers and clinicians new to this approach the online support network and other resources can be accessed via the IPA website (<http://www.ipa.bbk.ac.uk/home/>).

This paper firstly explores the theoretical basis of IPA and the process of data analysis. This is followed by an example of IPA in action with reference to the authors' own work about the lived experience of individuals with cerebellar ataxia.

INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS

Interpretative Phenomenological Analysis is an approach to qualitative research concerned with exploring and understanding the lived experience of a specified phenomenon (Smith, 2004). As a methodology in its own right rather than simply a means of analysing data, IPA involves the detailed examination of participants' 'lifeworlds'; their experiences of a particular phenomenon, how they have made sense of these experiences and the meanings they attach to them (Smith, 2004). IPA was introduced by Jonathan Smith, in his seminal paper of 1996, as an alternative but complementary approach to the more established quantitative and qualitative

methodologies in the psychology field (e.g. qualitative approaches such as grounded theory, conversation analysis, narrative psychology). Since then Smith and others have developed and refined the philosophical and theoretical underpinnings of the approach, see for example Eatough and Smith, (2008); Larkin, Watts and Clifton (2006), Smith, (2004, 2007); Smith, Flowers and Larkin (2009). The method has flourished in health psychology (see Brocki and Wearden, 2006 for a review) and has also attracted interest in related fields such as social, clinical and counselling psychology (Smith, 2004). Although firmly embedded in psychology, Smith, Flowers and Larkin (2009) have welcomed and encouraged those without formal psychology training such as occupational therapists and physiotherapists, to use IPA to answer psychological questions of importance to their discipline.

IPA researchers working in health are usually interested in exploring the lived experience of longer term disruptions to physical or mental health. IPA work may also look beyond the direct experience of the individual with the health condition to focus instead on the specific experiences of significant others such as fathers, mothers or siblings (see for example Hill, Higgins, Dempster and McCarthy, 2009). Whilst IPA researchers continue to explore a diverse range of health conditions, there is some indication that research questions are becoming focused on more specific concerns within a particular health condition, (see for example, Williamson, Simpson and Murray, 2008). A growing body of IPA work has enabled the voices of often under-researched groups to be heard e.g. children (Petalas et al, 2009), people with intellectual impairment (Clarkson, Murphy, Coldwell and Dawson, 2009), those with dementia (Clare et al, 2008) and individuals with psychosis (Quin, Clare, Ryan and Jackson, 2009). The majority of IPA work is somewhat disease or impairment focused (Reid, Flowers and Larkin, 2005). However, there is some indication that IPA researchers are also beginning to investigate the positive strategies and attributes which contribute to quality of life whilst living with a particular health condition (e.g. Reynolds and Prior, 2003; Reynolds, Vivat and Prior, 2008). There is also a growing

interest in exploring service users' and health care practitioners' experiences of services and health care processes (see for example Holly et al, 2009a, b and Thompson, Powis and Carradice, 2008).

The key theoretical perspectives of IPA are; phenomenology, interpretation (hermeneutics) and idiography (Smith, 2004, 2007; Smith, Flowers and Larkin, 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.

Phenomenology

Phenomenology is both a philosophy and a family of research methods concerned with exploring and understanding human experience (Langdridge, 2007).

Researchers using phenomenological methods aim to uncover the meaning of an individual's experience of a specified phenomenon through focusing on a concrete experiential account grounded in everyday life (Langdridge, 2007), for example the experience of living with Parkinson's disease (Bramley and Eatough, 2005); or the experience of living with an artificial limb (Murray, 2004). IPA is therefore connected to the core principles of phenomenology through paying respectful attention to a person's direct experience, and by encouraging research participants to tell their own story in their own words (Smith, Flowers and Larkin 2009). The purpose of the literature review in IPA, for example, is to learn about the phenomenon of interest and to identify a gap in what is known about the particular phenomenon but the literature is not subsequently used to inform data collection in a rigid way (Smith, 1999; Smith, Flowers and Larkin, 2009). In some forms of phenomenology i.e. those grounded more strongly in Husserlian rather than Heideggarian philosophy, the researcher attempts to bracket (or set aside) pre-defined theories and assumptions at this design phase so that data collection can be truly exploratory and participant

led. The extent to which this is possible is discussed below but crucially the IPA researcher should aim to follow the participant in novel and unanticipated directions as the story of their experience unfolds (Smith and Osborn, 2008).

IPA is also firmly anchored to key phenomenological understandings of lived experience as context-dependent and contingent upon social, historical and cultural perspectives (Eatough and Smith, 2008; Smith, Flowers and Larkin, 2009). Royal, Reynolds and Houlden (2009), for example, used IPA to explore the experience of returning to work following recovery from Guillain-Barré syndrome. These authors highlighted how restoration of a familiar sense of self was challenged by the response of others in the workplace and the participant's sensitivity to culturally acceptable norms of behaviour and appearance; these cultural imperatives were experienced and evaluated in idiosyncratic ways which varied with the participants' particular circumstances and status in the workplace. IPA researchers therefore articulate phenomenological concepts through their understanding that experience is not only individually situated and based on personal biographies, but also intrinsically bound up with and contingent upon relationships with others, coloured and shaped by society, culture and history (Eatough and Smith, 2008). Readers who are interested in the philosophical basis of phenomenology are referred to the following accessible sources; Smith, Flowers and Larkin (2009) for the philosophical basis of IPA, Langdrige (2007) for the philosophical basis of phenomenological psychology and Dahlberg, Dahlberg and Nyström (2008) for a more detailed overview of lifeworld research based on phenomenological philosophy. Moran (2000) offers a detailed but comprehensible introduction of phenomenology as a central strand of twentieth century philosophy.

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, Watts and Clifton 2006; Smith, 2007; Smith, Flowers and Larkin, 2009; see also Moran, 2000). Schleiermacher was a theologian concerned with the interpretation of biblical texts. 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 (Moran, 2000; Smith, Flowers and Larkin, 2009). 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 researchers when analysing the texts of research participants (Smith, 2007; Smith, Flowers and Larkin, 2009). They accept that a phenomenon is experienced by an individual in a particular and unique way and yet it is lived within a shared context. This, in turn, has resonance with the phenomenological theories discussed above. Schleiermacher's theories form a significant touchstone for IPA because he also suggested that an effective analysis, based on a linguistic as well as a psychological interpretation, would find meaning *beyond* the immediate claims of the individual; it would reveal more about a person than that person is aware of themselves (Smith, Flowers and Larkin, 2009).

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 (Larkin, Watts and Clifton, 2006). In this respect, all enquiry

starts from the enquirer's perspective, from the basis of their experience. Rather than setting aside or bracketing preconceptions and assumptions in advance of an enquiry, IPA researchers work from a Heideggerian perspective and *try* 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, Flowers and Larkin, 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, Watts and Clifton, 2006:108). This 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, Flowers and Larkin, 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 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 (Moran, 2000). So for Heidegger and IPA, phenomenology involves hermeneutics. 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 (Larkin, Watts and Clifton, 2006). Ultimately a rich and nuanced understanding of the phenomenon should be revealed, based on interpretative effort and 'hard won insights' (see Moran 2000:10) but a perfect understanding of the essence of the experience will always remain hidden.

Gadamer's perspectives are aligned with those of Heidegger and re-emphasise that the lived experience of the interpreter is both a way into the text as well as a hindrance to understanding the text. The interpreter's preconceptions may be identified in advance or may only emerge through the process of interpretation; as meaning emerges through interpretative effort, these preconceptions are adjusted prompting new questions to be asked of the text and in turn new meanings emerge (Moran, 2000; Smith, Flowers and Larkin, 2009).

Smith, Flowers and Larkin (2009:37) neatly summarise the co-dependency of interpretation 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). 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. 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, Flowers and Larkin, 2009).

In IPA, data collection starts the process of uncovering an understanding of the phenomenon in question. Interviews are commonly used and questions are exploratory and semi-structured. The process is dynamic, and what emerges is a co-construction built by the ebb and flow between the participant and the researcher. Data analysis continues in this vein; as the researcher begins to develop an understanding of the phenomenon, more informed questions can begin to be asked of the text. 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. The researcher then explains and interprets the meaning of the participant's account during the analysis and writing up. Smith and Osborn (2003:51) used the term 'double hermeneutic' to emphasise the two interpretations involved in this process; 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, Flowers and Larkin, 2009). The circularity of the process (questioning, uncovering meaning, and further questioning), involved in interpreting and understanding a phenomenon is called the hermeneutic circle (Moran, 2000; Smith, 2007; Smith, Flowers and Larkin, 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, and secondly a probing, more critical analysis based on the deeper interpretative work of the researcher (Eatough and Smith, 2008; Larkin, Watts and Clifton, 2006; Smith, Flowers and Larkin, 2009). This double layered hermeneutic analysis resonates with the classical hermeneutics of Schleiermacher but it is applied within a postmodern context. 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 unfolds during the construction as well as during the analysis of these 'texts'. This difference between classical hermeneutics and hermeneutics as applied to research in the human sciences is discussed further by Smith (2007).

Idiographic Inquiry

Idiography is concerned with the particular, the distinct experiences of particular people and the particular contexts in which those experiences occur (Eatough and Smith, 2008; Smith, Flowers and Larkin, 2009; Smith, Harré and Van Langenhove, 1995). The case is central to the inquiry; the researcher attempts to understand as much about one case before moving onto the next. Findings from the first case are set aside (as far as is possible), through dynamic bracketing, in order to maintain sensitivity to each person's unique story (Smith, Flowers and Larkin, 2009). IPA has changed somewhat in this respect over the years, for example Smith and Osborn (2003) suggested that themes from the first case could be used to inform the subsequent analysis of the other cases however, a firmer commitment to the idiographic approach has been articulated in more recent writings (Smith, Flowers and Larkin, 2009). Finally a cross-case analysis is conducted. At this final stage however, the analysis attempts to remain faithful to the individual 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). For example, Smith (1999) conducted a study about the psychological processes of becoming a mother ($n = 3$). One shared theme identified that major social gatherings triggered reflections about the participant's sense of identity and her role within her own family. However, each participant experienced this in different ways; one experienced a heightened sense of complex family connections, another sensed that her pregnancy distanced her from her partner and

the third acknowledged the occasion as a public recognition of her emerging identity as a mother. So, a pattern emerged in the data from which an overarching theme could be constructed but each participant's experiences were grounded in their particular circumstances and perceptions. This facility for highlighting unique perspectives as well as shared experiences is one of the cornerstones of IPA (Smith, 2004, Smith and Osborn, 2008).

Consistent with the idiographic approach, small samples are commonly advocated for IPA studies (Smith, Flowers and Larkin, 2009; Smith and Osborn, 2008) and an increasingly strong commitment to $n = 1$ studies has been encouraged (Eatough and Smith, 2008; Smith, Flowers and Larkin, 2009). However, in a 2006 critical review of IPA, sample sizes ranged from 1-35 with most studies falling in the middle of this range (Brocki and Wearden, 2006). Since then it seems that the mean sample size of published studies continues to follow this trend (see table 1 for an indicative overview of studies published from 2006-2009).

Insert table 1 about here

Applying the findings of IPA research to therapeutic practice

For the practitioner, the value of qualitative research is that the findings are attuned to issues which could be usefully explored in practice (Green and Britten, 1998). IPA as an approach to research can be used to challenge conventional discourse or ways of thinking. The strong commitment to idiography may raise questions about the generalisability and clinical utility of IPA studies. However, IPA researchers do not deny the importance and relevance of group and population studies, nor is IPA opposed to making more general claims; it does so only through a careful step-by-step approach (Smith, Flowers and Larkin, 2009; Smith and Osborn, 2008). Jumping in too quickly, trapping what emerges into systems and frameworks that fit current

discourses, risks misrepresenting the reality of the experience and may lead to false assumptions and misunderstandings (Smith, Harré and Van Langenhove, 1995). Stephens (1982) distinguished between horizontal generalisability and vertical generalisability. Horizontal generalisability points towards findings that are applicable across settings whereas vertical generalisability is concerned with building interpretative theory. Vertical generalisability means that the findings from qualitative research, such as IPA, should be considered by readers in terms of their ability to enhance understanding, enlarge insight and contribute to existing theories and the generation of new hypotheses (Johnson, 1997; Kearney 2001; Yardley, 2008). Thus, as with other forms of research findings, readers interrogate the published findings to see whether there is resonance with their experiences and whether the findings provoke a re-evaluation of what was considered known or understood about the investigated phenomenon (Johnson, 1997). Physiotherapists, for example, may consider whether the new understandings contribute to clinical reasoning processes. The researchers themselves also have a responsibility to discuss findings through interrogation of the extant literature and to point out and debate the connections as well as the dissonance between the findings of the study and the prevailing discourse or evidence (Smith, 2004). For example, in the study described above, Smith (1999) cautiously discussed the resonance of his findings with existing theory (identity is mutable and shaped by social experiences) and illustrated the utility of the theory within a particular locale – the transition to motherhood. In this respect Smith fleshed out an existing theory and enlivened it by showing how the reassessment of identity unfolded during pregnancy. Furthermore Smith (1999) suggested other lines of enquiry to explore the theory through looking at the experiences of other women going through the same and different life transitions. Similarly, Dean, Smith, Payne and Weinman (2005) used IPA to explore physiotherapists' and patients' experience of (non)adherence to therapeutic exercise for low back pain. The findings challenged existing social cognitive models,

particularly the threat appraisal model. This model failed to take account of the complex interaction of social, personal and cultural factors that shaped the patients' understanding not only of low back pain but also the relevance of exercise in managing the condition. For example if the participant believed they had a serious back problem it emerged that they would be unlikely to adhere to exercise therapy. Clinicians were therefore advised to take the time to understand their patients' beliefs about their back pain before prescribing exercise. Participants also described back pain as an interruption to normal life, exercise was framed as an additional interruption, and participants with this perception were less likely to adhere to prescribed exercise. Clinicians were advised to discuss the commonality of low back pain with patients, to explain its cyclical nature and to not only help patients reframe exercise as part of everyday life, but also to reframe low back pain as a routine part of everyday life that can be managed alongside other everyday activities. Thus the authors offered important insights for physiotherapists with regard to helping patients reinterpret their understanding of exercise in the management of low back pain.

Data Analysis

A distinct, systematic but not prescriptive process for analysing data, based on a thematic analysis, has been described by Smith and colleagues, and readers are referred to these texts for specific information about the analytic procedures for IPA (Larkin, Watts and Clifton, 2006; Smith, 1999; Smith, Flowers and Larkin, 2009; Smith and Osborn, 2008). Data analysis is guided by an attitude of openness and a willingness to dwell in the data, consistent with the approach taken towards data collection. The focus remains the participant's attempt to make sense of their experience and the analysis progresses from the particular to the shared and from the descriptive to the interpretative (Smith, Flowers and Larkin, 2009). A loose structure is described consisting of several phases. Briefly these consist of reading and re-reading the text, followed by making initial notes of points of interest. Note

taking may include key descriptive comments and phrases, or linguistic characteristics e.g. hesitancy, metaphor, repetition; as well as more interpretative conceptual comments where the researcher begins to ask questions of the text (e.g. what does this description illustrate about the participant's understanding of this phenomenon?). The next stage involves a move away from working directly with the transcripts to working with the initial notes to develop emergent themes. A certain amount of pruning will occur at this stage; the researcher works to maintain the depth and complexity by focussing on the most important and interesting data whilst reducing the volume. A second researcher is valuable at this stage to help ensure that the most relevant data are retained and to increase sensitivity and openness towards the meanings within the data. Next the researcher looks for connections across the emergent themes. The important concept here is that this process is not prescriptive; there are many ways of working with the data, for example similar themes may be clustered together and given a name describing the whole – a super ordinate theme; for others an emerging theme may describe other themes and itself become the super ordinate theme. At the end of this stage however, it should be possible to illustrate how the emergent and super ordinate themes have been constructed using either a table or figure. As described above the same process is undertaken for further cases (in studies where $n > 1$), and finally a cross-case analysis is conducted which involves looking for differences as well as similarities, identifying connections and renaming themes as a deeper understanding of the data is developed (Smith, Flowers and Larkin, 2009).

The final account should be plausible; because of the interpretative stance IPA researchers are not looking to produce a definitive analysis. The data presented should support the claims made by the researchers but it is unlikely that an independent researcher would identify exactly the same themes in exactly the same way; the emphases may differ, based on the researcher's personal contexts and experiences. However, the researchers might consider providing an audit trail that

could be independently scrutinised to trace the development of the analysis from transcript to final presentation of themes (Smith, Flowers and Larkin, 2009).

There are many ways to judge the validity of qualitative research and whilst there is no specific method that can be applied to IPA, Smith and colleagues (2009) favour the 'four principles' approach of Yardley (2000; 2008). In this assessment of quality reviewers are asked to look at the research from the perspective of sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance. With particular reference to IPA reviewers might also be additionally concerned with looking for; a commitment to the idiographic approach, attention directed towards an experiential account of significance to the participant(s), interpretative as well as hermeneutic analysis and caution in moving towards general claims (Smith, Flowers and Larkin, 2009).

IPA IN ACTION: EXPLORING THE LIVED EXPERIENCE OF PEOPLE WITH ATAXIA

Having clarified the theoretical and practical orientations of IPA this next section provides a segment of data analysis from a study that used IPA to explore the lived experience of people living with cerebellar ataxia. The study aimed to explore inductively how cerebellar ataxia is understood by the people who live with it and how participants made sense of their experiences. The study was approved by the School of Health Sciences and Social Care Research Ethics Committee, Brunel University. Rather than following the traditional research report this section offers a detailed example of data analysis and aims to particularly illuminate the interpretative work of the researcher which is critical to IPA methodology but which is often hidden in the final published account.

Data Collection

Participants were members of Ataxia UK an organisation for people who have a progressive ataxia as part of an inherited or idiopathic condition but not as the result of trauma or as part of another progressive condition such as multiple sclerosis. Invitations to participate were placed on the Ataxia UK website and the members' journal, in addition flyers were sent to regional support groups. Twelve people with ataxia were recruited and interviewed by the first author; the interviews were recorded and transcribed in full.

Data Analysis

The following offers a detailed examination of two passages from one participant, Jim¹, who had lived with cerebellar ataxia for over twenty years and at the time of the interview was in his late forties. The extracts from Jim's account have been used to demonstrate a layered interpretation moving from a phenomenological, empathic account to a more critical and interrogative analysis. The extracts are brief; the intention is to give a flavour of IPA analysis rather than to present a definitive account. 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 [...] 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 verbal '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 falls, what concerns him most are other people's responses and beliefs about what this disordered gait 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 someway discreditable or offensive to others.

At a more hermeneutic level this passage 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 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 the public domain, he is constantly 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, play down or minimise what is in fact uncontainable and at large. What is constructed through this 'self-talk' is fragile; although Jim tells himself that the ataxia is no big deal 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. Also, Jim locates his negative experiences within a wider social context. Not only does he suffer but his wife and children also suffer, and in a broader context, other people with disabilities suffer in the same way. In this respect Jim feels both different and similar to others; he is different and exceptional in the sense of his own particular experiences and yet he locates those perceived differences within the experiences of other people.

To support this interpretation, further evidence would be needed from elsewhere in the data. 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. [...] but having something so obvious as a walking stick, it's just a visible sign to everybody – yes I am definitely different.'

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 more than that, it comes back to the idea of containment and concealment. He 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 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. 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. 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. Secondly, the walking stick itself is a stigma symbol; it serves as a signal to others of *'difference'*. The stick is an artefact that symbolises a group identity that sits uncomfortably with Jim; he may construct using a stick as a sign of ageing or perhaps worse, vulnerability.

In summary, interpretative work cautiously suggests that stigma could be identified as a concern within Jim's account. It seems that Jim has internalised a view that frames disordered walking as undesirable and shameful and this is inferred through his encounters with others. Jim's ongoing 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 general sense, as a means of keeping the ataxia and its longer term implications at bay.

The next step in data analysis involves looking for patterns and indications of similar examples of the same overarching theme in other analysed cases (convergence), and to demonstrate how an overarching theme emerges in the other cases whilst maintaining the stance towards individual particularity (Smith, Flowers and Larkin, 2009) . For this paper, two further examples of felt stigma are discussed.

The following extract is taken from Stella's account. Stella is in later mid-life; she is retired and lives alone. Stella has 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.'*

For Stella, public scrutiny, *'If I think people are watching me'*, effectively paralyses her, *'I just freeze and my legs won't work'*. From a phenomenological perspective, it seems that Stella has also come to understand that walking discloses something about her that others consider discreditable. People may not actually stand in judgement of her and she may only *'think'* that she is being watched, but for Stella the regard of others and even just the thought of being watched has a profound effect. Momentary freezing could be understood as a means of temporarily resisting what Stella anticipates as a harsh and potentially overwhelming public appraisal. A brief paralysis might also give Stella pause, a short-lived hiatus where she can shore up her resources, bolstering herself to withstand scrutiny. However, it seems that both the disordered walking and *'freezing'* are problematical for Stella.

At a more hermeneutic level the pauses in the extract seem to signify that Stella finds 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 diagnosed it as a *'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 if she was being rational she would be able to overcome her difficulties.

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, 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 therefore feel responsible for this behaviour, as if the 'phobia' is her fault.

One further extract from Stella's account adds another layer to this interpretation:

Stella: *'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 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 to be 'handicapped' 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. In this extract Stella frames the walking stick itself as disabling, something for Stella that constrains 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 a 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 are 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 disabled and dependent, in the 'not yet' rather than the 'already' realm of personal experience.

The following extract is used here as a further example of stigma associated with living with ataxia but it too has a slightly different quality from the other accounts considered. Susan is in later mid-life, retired and lives with her husband. She has lived with ataxia for many years but was not certain about the date of onset or diagnosis. Like Stella and Jim, Susan recounts a social situation where she anticipates unfavourable scrutiny and rejection not because her disordered gait as such draws attention but because it is inconsistent and perhaps not 'bad enough' to be accepted by others.

Susan: *'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.'*

As with the other extracts, 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 that people, particularly family, pass judgement, not necessarily about her disordered walking but about the legitimacy of her condition, as fluctuating disability perhaps lacks credibility. Susan does not always need a walking stick; she can manage if she is not too tired or if she can reach for furniture for support. This inconsistency seems to be misunderstood by her family, who know about the ataxia, *'She doesn't seem that bad'*. Like Jim, Susan anticipates their hostile gaze and hears their critical voices. Susan describes an *'inferiority complex'*, pointing towards feelings of personal inadequacy that seem to stem from these public encounters. Rather than face that sort of 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 she engages in self-talk; *'I find it easier not to socialise and I can manage without socialising really'*, possibly as a means of justifying and coping with the consequences of her decision.

These extracts from three separate accounts share a concern with public scrutiny and exposure of the self that are similar but each participant's experience is personally situated. For each case the 'gaze', whether real or apparent, is identified as the trigger for inferring oneself as different or harbouring a characteristic that is in some way undesirable or diminishing. For Jim and Stella, public scrutiny provokes 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 each of these extracts the individuals concerned describe context specific and personal strategies to resist or manage the stigma associated with living with ataxia. For example it seems significant that Jim is married, employed and has teenage children. His

account is concerned with family and work considerations, and illustrates not only how he perceives himself in public but also how this is bound up with his role within the family and (as it emerges later in his account) helping others understand disability issues in the workplace. For Stella the experiences she described were not family orientated, she lives alone and for the most part deals with her experiences of ataxia on her own. She does not have the support of others who may confer 'acceptability' in social situations. Susan, by comparison, lives with her husband and has a close immediate family. With this sort of support perhaps Susan's withdrawal from public life is less isolating or more sustainable than it would be for someone living under Stella's particular circumstances.

In summary, the accounts of these three participants would lend support to the construction of a convergent theme that cautiously points towards the ways in which felt stigma may manifest itself in the lived experience of ataxia. Further explication of the theme would necessarily discuss the idiographic accounts as well as interrelated issues concerned with agency, control and the influence of stigma on the sense of self.

Discussion

Here, a brief discussion is offered of the preliminary theme suggested above. Physiotherapists are likely to encounter many people who live with potentially stigmatising conditions and, through their actions, physiotherapists may either emphasize or diminish the shame and stigma associated with living with these conditions (Sim, 1990). Physiotherapists who have an understanding of the contextualised experience of stigmatising conditions and how this impacts on the lives of patients, might be better placed to help patients cope with stigma and may be more able to adopt approaches that best fit a patient's particular circumstances and experiences.

Goffman (1963) suggested that people living with stigmatising conditions constantly engaged in activities to preserve fragile personal and social identities. Stigma management included information control, the development of covering behaviours and 'great effort to keep the stigma from looming large' (Goffman, 1963:125). Management strategies described by Goffman (1963) were also evidenced by participants in the ataxia study; concealment of stigma symbols (Jim), maintaining physical distance (Susan), and reconstituting social behaviour to minimise conspicuous 'motor impropriety' (Stella). A similar sense of shame associated with 'rule breaking in public' was described by Nijhof (1995:193) in a study concerned with the experience of living with Parkinson's disease. Toombs (1995) also spoke of the shame she felt and the covering behaviours she adopted with each transition she made from walking independently to becoming a full time wheelchair user as part of living with multiple sclerosis. More recently women with spinal cord injury have talked about their experience of the 'stare' and adopting social isolation strategies as part of a process of coming to terms with their changed body (Chau et al, 2008).

This small piece of analysis, taken from a larger IPA study, cautiously points towards an understanding that living with ataxia may, for some individuals, involve a problematic and shameful 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. Further, the analysis revealed that people with ataxia may similarly engage in behaviours designed to minimise exposure of symptoms in public which in turn have the unfortunate consequence of leading to diminished life experience. Finally, the findings suggest that ataxia should, at least in part, be understood as a 'located illness' (Nijhof, 1995), situated and experienced in the social world and not as 'simply' a physical disorder. This contextual understanding of the lived experience of ataxia illustrates the rich insights that can be

gained from adopting a biopsychosocial perspective as compared to a more biomedical approach towards research and practice.

These findings are both new with respect to understanding the experience of living with ataxia and yet resonate with other studies of people living with motor impairment such as Parkinson's disease (Bramley and Eatough, 2008; Nijhof, 1995), multiple sclerosis (Grytten and Måseide, 2005, 2006; Toombs, 1995) and spinal cord injury (Chau et al, 2008), as well as other less obviously aligned conditions such as Tourette's Syndrome (Davis, Davis and Dowler, 2004). Identification of recurrent themes and findings that are consistent with other studies is important in establishing a corpus of evidence that may be used to point towards the development of stronger theoretical statements or to facilitate the often incremental translation of research findings into clinical practice. The new work provides insights from a previously under-researched population which may further enrich understanding of the phenomenon in more general terms. In addition, intensive fine grained, idiographic analysis, which prioritises the experiential claims of individuals, provides rich and contextualised accounts that can perhaps flesh out the more general claims described via conventional thematic analysis (Kearney, 2001).

Implications for Working with People with Ataxia

The recognition of the significance of stigma as experienced in a wide range of health conditions and the lack of an evidence base for interventions has led to cross disciplinary interest in developing a science of stigma (Keusch, Wilentz and Kleinman, 2006). Neurophysiotherapists clearly have a role here; the experiences of stigma talked about in this study seem to be intimately related with the work of physiotherapy. Through combining a traditional orientation towards the physical body with an understanding of the 'body-as-lived' (Marcum, 2004; Whalley Hammell, 2006), physiotherapists are perhaps well placed to consider stigma and help patients recognise and manage their own cognitions about stigma, shame and the social

impact of living with a neurological condition. There is evidence to suggest that protective behaviours can be learned and that resilience and empowerment can be developed through support and education (Edward and Warelow, 2005). Radley (1997:65) suggested that the implication of phenomenological research 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.' Only if practitioners understand how these concepts are bound together in the lives of the people concerned will they be in a position to alleviate suffering and contribute to the maintenance of health (Radley, 1997). The pattern of physiotherapy practice characterised by intensive, often long term contact with patients (Dean, 2009), places physiotherapists in a position to both appreciate the personal significance of patients' narratives and their complexities and to offer practical support. An awareness of cognitive behavioural therapy, for example, might be relevant to help physiotherapists become more aware of how patients talk about their condition and everyday problems, and in turn it may be a useful intervention to help patients challenge their unexamined assumptions and to consider alternative ways of framing their experience (see for example Padesky and Greenburger, 1995).

IPA RESEARCH AND PHYSIOTHERAPY

Rigorously conducted qualitative research provides a more advanced level of evidence than the anecdotal evidence which formulates much of clinical practice (Green and Britten, 1998; Kearney, 2001). The idiographic nature of IPA, paying close attention to individual accounts, may disclose interesting and valuable insights for practice that challenge physiotherapists' every day assumptions. IPA might also provide a foundation for developing a more empathic and contextualised understanding of illness-as-lived that in turn enables physiotherapists to provide services and treatments that are consistent with patients' concerns and priorities (see for example Jensen, 1989; Kearney, 2001; Toombs, 2001). Without this detailed,

attentive and fine grained approach to research much of what is central to a patient's experience of a health condition may remain undisclosed.

For physiotherapy researchers with an interest in qualitative enquiry the decision about whether to use IPA or another qualitative method will rest on pragmatic as well as methodological concerns. This section briefly considers where IPA sits in relation to two other qualitative methods; firstly grounded theory because this is often seen as the main alternative to IPA (Smith, Flowers and Larkin, 2009) and secondly narrative analysis because its theoretical foundations overlap somewhat with those of phenomenology (Smith, Flowers and Larkin, 2009). In comparison to IPA, grounded theory uses larger samples and is directed at a more macro level of analysis.

Grounded theory is concerned with developing codes and categories from qualitative data that are used to construct theories about the topic of interest. Unlike IPA, grounded theory adopts theoretical sampling techniques whereby the emerging categories and theory are tested and refined through the ongoing identification and recruitment of participants. Sampling continues until saturation, the point at which no new data emerges from further sampling (Glaser and Strauss, 1967). IPA differs from grounded theory because of its focus on making sense of individuals' lives, and in its careful, step by step approach towards making more general claims (Smith, Flowers and Larkin, 2009). Narrative analysis is concerned with exploring the life story of an individual or a few individuals and combines this with an explicit interest in the social backdrop of the recounted life (Hydén, 1997). The story is the object of investigation, researchers look at how narrators impose order on the narrative and how they place themselves within it e.g. as protagonist or victim (Riessman, 1993). Importantly and unlike IPA, the narrative account is not deconstructed into themes. Researchers accept the structure imposed on the story by the narrator and focus on analysing why the account was structured in that way and how the narrator made sense of their story (Riessman, 1993).

IPA is an evolving approach to qualitative research and as such it presents both an opportunity and a challenge for physiotherapy researchers. IPA should be seen as an opportunity to exploit an area of enquiry that has to date been under-explored by physiotherapy researchers. IPA is established in the field of health psychology and there is a considerable body of work which physiotherapists can draw upon when developing research questions. However, as there is only one critical review of IPA (Brocki and Wearden, 2006) it means that there is little to help researchers distinguish what is 'good' IPA research from that which is of a lower quality. Smith, Flowers and Larkin (2009) go some way towards establishing the basic tenets of good IPA research but this is an area ripe for further systematic review. Furthermore, physiotherapy researchers may need to undertake additional work in order to engage readers, funders and editors and to develop a broader understanding of IPA and its application to physiotherapy research and practice. Funding bodies for example may expect physiotherapists using IPA to be more explicit about the application of the findings to practice in terms of clinical utility and validity than is perhaps usual in the IPA literature. Rauscher and Greenfield (2009) have argued the case for using mixed methods in physiotherapy research and whilst IPA seems an obvious partner for quantitative methods because it can help researchers contextualise quantitative findings, mixed methods research could also be seen as a pragmatic means of introducing IPA into 'mainstream' physiotherapy research. The theoretical underpinning of IPA can be somewhat off putting, however all phenomenological research requires a basic understanding of the broader philosophical underpinnings of the method (Creswell, 2007) and whilst initially this may seem daunting, useful and concise resources are easily accessible, particularly within the IPA community. Finally, one of the difficulties of any phenomenological research is in accounting for the understanding and influences of the researcher and in making decisions about where to introduce these perspectives into the study (Creswell, 2007). This is an area

of lively debate and useful resources are available to support researchers new to the field (see for example Finlay, 2002, 2008).

CONCLUSION

The landscape in which physiotherapists practise continues to develop, bringing with it new and evolving challenges. For example, physiotherapists are working with a growing population of people who are now living into adulthood with what were once considered childhood conditions (e.g. adults living with cystic fibrosis and muscular dystrophy); people who live with HIV AIDS are coming to understand it as a long term rather than a life limiting condition; pioneering patients and therapists are grappling with emerging technical innovations such as electrical limb implants, limb transplantations and electrotherapies that can directly influence neuronal plasticity. Progress in therapeutic, pharmacological, surgical and other medical and non-medical fields will continue to transform the rehabilitation possibilities and the experiences of people living with long term health conditions, whilst for others such progress remains stubbornly slow. A better understanding of what it is like to live with these conditions and how rehabilitation, and in particular physiotherapy, is perceived by clients remains an important research and clinical endeavour. IPA offers a means of developing this understanding and thereby has the potential of improving the experience of rehabilitation for people living with long term health conditions.

Transcript Extract Notation

[...] editorial elision where non-relevant material has been eliminated

... a pause in the participant's account

¹In keeping with the idiographic approach but to preserve anonymity, pseudonyms have been used, the names were chosen by the researchers.

Declaration of interest

None

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References

- Bramley N, Eatough V 2005 The experience of living with Parkinson's disease: an interpretative phenomenological analysis case study. *Psychology and Health* 20:223-235.
- Brocki JM, Wearden AJ 2006 A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and Health* 21:87-108.
- Chau L, Hegedus L, Praamsma M, Smith K, Tsukada M, Yoshida K, Renwick, R 2008 Women living with spinal cord injury: perceptions about their changed bodies. *Qualitative Health Research* 18:209-221.
- Clare L, Rowlands J, Bruce E, Surr C, Downs M 2008 The experience of living with dementia in residential care: an interpretative phenomenological analysis. *Gerontologist* 48:711-720.
- Clarkson R, Murphy GH, Coldwell JB, Dawson DL 2009 What characteristics do service users with intellectual disability value in direct support staff within residential forensic services? *Journal of Intellectual and Developmental Disability* 34, 4, 283-289.
- Creswell JW 2007 *Qualitative enquiry and research design: choosing among five approaches*, 2nd edn. Thousand Oaks, Sage.
- Curry LA, Nembhard IM, Bradley EH 2009 Qualitative and mixed methods provide unique contributions to outcomes research. *Circulation* 119:1442-1452.
- Dahlberg K, Dahlberg H, Nyström M 2008 *Reflective lifeworld research*, 2nd edn. Lund, Studentlitteratur.
- Davis KK, Davis JS, Dowler L 2004 In motion, out of place: the public space(s) of Tourette syndrome. *Social Science and Medicine* 59:103-112.
- Dean E 2009 Physical Therapy in the 21st century (part 1): towards practice informed by epidemiology and the crisis of lifestyle conditions. *Physiotherapy Theory and Practice* 25:330-353.
- Dean SG, Smith JA, Payne S 2006 Low back pain: exploring the meaning of exercise management through interpretative phenomenological analysis (IPA). In: Finlay L, Ballinger C (eds) *Qualitative research for allied health professionals: challenging choices* pp 139-155. Chichester, John Wiley and Sons Ltd.
- Dean SG, Smith JA, Payne S, Weinman J 2005 Managing time: an interpretative phenomenological analysis of patients' and physiotherapists' perceptions of adherence to therapeutic exercise for low back pain. *Disability and Rehabilitation* 27:625-636.
- Dickson A, Allan D, O'Carroll R 2008 Biographical disruption and the experience of loss following spinal cord injury: an interpretative phenomenological analysis. *Psychology and Health* 23:407-425.

- Eatough V, Smith JA 2008 Interpretative phenomenological analysis. In: Willing C, Stainton-Rogers W (eds) *The Sage handbook of qualitative research in psychology*, pp 179-194. Los Angeles, Sage.
- Edward K-L, Warelow P 2005 Resilience: when coping is emotionally intelligent. *Journal of the American Psychiatric Nurses Association* 11:101-102.
- Finlay L 2008 A dance between the reduction and reflexivity: explicating the 'phenomenological psychological attitude'. *Journal of Phenomenological Psychology* 39:1-32.
- Finlay L 2002 'Outing the researcher': the provenance, process and practice of reflexivity. *Qualitative Health Research* 12:531-545.
- Glaser BG, Strauss AL 1967 *The discovery of grounded theory: strategies for qualitative research*. New York, Aldine De Gruyter.
- Glasscoe C, Smith JA 2008 Through a mother's lens: a qualitative analysis reveals how temporal experience shifts when a boy born pre-term has cystic fibrosis. *Clinical Child Psychology and Psychiatry* 13:609-626.
- Goffman E 1963 *Stigma: notes on the management of spoiled identity*. London, Penguin.
- Green J, Britten N 1998 Qualitative research and evidence based medicine. *British Medical Journal* 316:1230-1232.
- Grytten N, Måseide P 2005 'What is expressed in not always what is felt': coping with stigma and the embodiment of perceived illegitimacy of multiple sclerosis. *Chronic Illness* 1:231-243.
- Grytten N, Måseide P 2006 'When I am together with them I feel more ill': the stigma of multiple sclerosis experienced in social relationships. *Chronic Illness* 2:195-208.
- Hill K, Higgins A, Dempster M, McCarthy A 2009 Fathers' views and understandings of their roles in families with a child with acute lymphoblastic leukaemia. *Journal of Health Psychology* 14, 8, 1268-1280.
- Holly J, Hale ED, Treharne GJ, Carroll D, Kitas GD 2009a 'All singing from the same hymn sheet': healthcare professionals' perceptions of developing patient education material about the cardiovascular aspects of rheumatoid arthritis. *Musculoskeletal Care* 7, 4, 256-271.
- Holly J, Hale ED, Treharne GJ, Carroll D, Kitas GD 2009b 'Extra information a bit further down the line': rheumatoid arthritis patients' perception of developing educational material about the cardiovascular disease risk. *Musculoskeletal Care* 7, 4, 272-287.
- Hydén L-C 1997 Illness and narrative. *Sociology of Health and Illness* 19:48-69.
- Jensen GM 1989 Qualitative methods in physical therapy research: a form of disciplined inquiry. *Physical Therapy* 69:492-500.

- Johnson JL 1997 Generalizability in qualitative research: excavating the discourse. In: Morse JM (ed) *Completing a qualitative project: details and dialogue*, pp191-208. Thousand Oaks, Sage.
- Kearney MH 2001 Levels and applications of qualitative research evidence. *Research in Nursing and Health* 24:145-153.
- Keusch GT, Wilentz J, Kleinman A 2006 Stigma and global health: developing a research agenda. *The Lancet* 367:525-527.
- Langdridge D 2007 *Phenomenological psychology: theory, research and method*. Harlow, Pearson Prentice Hall.
- Larkin M, Watts S, Clifton E 2006 Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology* 3:102-120.
- Marcum JA 2004 Biomechanical and phenomenological models of the body, the meaning of illness and quality of care. *Medicine, Health Care and Philosophy* 7:311-320.
- Mattingly C 1993 Commentary on Shepard KF, Jensen GM, Schmoll BJ, Hack LM, Gwyer J Alternative approaches to research in physical therapy: positivism and phenomenology. *Physical Therapy* 73:98-101.
- Moran D 2000 *Introduction to phenomenology*. London, Routledge, Taylor & Francis Group.
- Murray CD 2004 An interpretative phenomenological analysis of the embodiment of artificial limbs. *Disability and Rehabilitation* 26:963-973.
- National Institute for Health Research 2008 *Transforming health care research: the first two years*, National Institute for Health Research progress report 2006-2008. Department of Health pp 53-54.
- Nijhof G 1995 Parkinson's disease as a problem of shame in public appearance. *Sociology of Health and Illness* 17:193-205.
- Padesky CA, Greenberger D 1995 *A clinician's guide to mind over mood*. New York, The Guildford Press.
- Petalas MA, Hastings RP, Nash S, Dowey A, Reilly D 2009 'I like that he always shows who he is': the perceptions and experiences of siblings with a brother with autism spectrum disorder. *International Journal of Disability, Development and Education* 56, 4, 381-399.
- Pullen SA, Povey RC, Grogan SC 2009 Deciding to attend cardiac rehabilitation: a female perspective. *International Journal of Therapy and Rehabilitation* 16:207-217.
- Quin RC, Clare L, Ryan P, Jackson M 2009 'Not of this world': the subjective experience of late onset psychosis. *Aging and Mental Health* 13, 6, 779-787.
- Radley A 1997 What role does the body have in illness? In: Yardley L (ed) *Material discourses in health and illness*, pp 50-67. London, Routledge.
- Rauscher L, Greenfield BH 2009 Advancements in contemporary physical therapy research: use of mixed methods designs. *Physical Therapy* 89:91-100.

Reid K, Flowers P, Larkin M 2005 Exploring lived experience. *The Psychologist* 18, 1, 20-23.

Reid J, McKenna H, Fitzsimmonds D, McCance 2009 The experience of cancer cachexia: a qualitative study of advanced cancer patients and their family members. *International Journal of Nursing Studies* 46:606-616.

Rennie DL 1999 Qualitative research: a matter of hermeneutics and the sociology of knowledge. In: Kopala M and Suzuki LA (eds) *Using qualitative methods in psychology*, pp 3-13. Thousand Oaks, Sage.

Reynolds F, Prior S 2003 'Sticking jewels in your life': exploring women's strategies for negotiating an acceptable quality of life with multiple sclerosis. *Qualitative Health Research* 13:1225-1251.

Reynolds F, Vivat B, Prior S 2008 Women's experiences of increasing subjective well-being in CFS/ME through leisure-based arts and crafts activities: a qualitative study. *Disability and Rehabilitation* 30:1279-1288.

Riessman CK 1993 *Narrative analysis. Qualitative Research Methods Series 30.* Newbury Park, Sage.

Royal E, Reynolds FA, Houlden H 2009 What are the experiences of adults returning to work following recovery from Guillain-Barré syndrome? An interpretative phenomenological analysis. *Disability and Rehabilitation* 31:1817-1827.

Shepard KF, Jensen GM, Schmoll BJ, Hack LM, Gwyer J 1993 Alternative approaches to research in physical therapy: positivism and phenomenology. *Physical Therapy* 73:88-97.

Sim J 1990 Physical disability, stigma and rehabilitation. *Physiotherapy Canada*, 42:232-238.

Smith JA 1996 Beyond the divide between cognition and discourse: using interpretative phenomenological analysis in health psychology. *Psychology and Health* 11:261-271.

Smith JA 2007 Hermeneutics, human sciences and health: linking theory and practice. *International Journal of Qualitative Studies on Health and Well-being* 2:3-11.

Smith JA 2004 Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology* 1:39-54.

Smith JA 1999 Towards a relational self: social engagement during pregnancy and psychological preparation for motherhood. *British Journal of Social Psychology* 38:409-426.

Smith JA, Eatough V 2006 Interpretative phenomenological analysis. In: Breakwell GM, Hammond S, Fife-Schaw C, Smith JA (eds) *Research methods in psychology*, pp322-341. London, Sage.

Smith JA, Flowers P, Larkin, M 2009 *Interpretative phenomenological analysis: theory, method and research.* Los Angeles, Sage.

Smith JA, Harré R, Van Langenhove L 1995 Idiography and the case study. In: Smith JA, Harré R, Van Langenhove L (eds) *Rethinking psychology*, pp 57-69. London, Sage.

Smith JA, Osborn M 2003 Interpretative phenomenological analysis. In: Smith JA (ed) *Qualitative psychology: a practical guide to research methods*, pp 51-80. London, Sage.

Smith JA, Osborn M 2008 Interpretative phenomenological analysis. In Smith JA (ed) *Qualitative psychology: a practical guide to research methods*, 2nd edn. pp 53-80. London, Sage.

Stephens M 1982 A question of generalisability. *Theory and Research in Social Education* 9:75-86. Cited in: Johnson JL 1997 Generalizability in qualitative research: excavating the discourse. In: Morse JM (ed) *Completing a qualitative project: details and dialogue*, pp191-208. Thousand Oaks, Sage.

Thompson AR, Powis J, Carradice A 2008 Community psychiatric nurses' experiences of working with people who engage in deliberate self-harm. *International Journal of Mental Health Nursing* 17, 3, 153-161.

Toombs SK 1995 The lived experience of disability. *Human Studies* 18:9-23.

Toombs SK 2001 The role of empathy in clinical practice. *Journal of Consciousness Studies* 8:247-258.

Whalley Hammell K 2006 *Perspectives on disability and rehabilitation: contesting assumptions, challenging practice*. Edinburgh, Churchill Livingstone, Elsevier.

Williamson C, Simpson J, Murray C 2008 Caregivers' experiences of caring for a husband with Parkinson's Disease and psychotic symptoms. *Social Science and Medicine* 67, 4, 583-589.

Yardley L 2008 Demonstrating validity in qualitative psychology. In: Smith JA (ed) *Qualitative Psychology: a practical guide to research methods*, 2nd edn, pp 235-251. Los Angeles, Sage.

Yardley L 2000 Dilemmas in qualitative health research. *Psychology and Health* 15:215-228.

Table 1 Indicative overview of sample size for IPA studies 2006-2009*

Total number of studies	Mean sample size	Range	Mode
136	12	1-100	8 (20/136)
Authors	Topic	Sample size	Nature of the sample
Clare et al 2008	Experience of living with dementia in residential care	$n = 80$	Unstructured conversations with men and women with moderate - severe dementia living in residential care homes.
Reid, McKenna, Fitzsimmonds and McCance 2009	Experience of cancer cachexia	$n = 27$	Purposive sampling of 15 people with cancer cachexia and 12 family members.
Dickson, Allan and O'Carroll 2008	Experience of loss and biographical disruption following spinal cord injury	$n = 8$	Purposive sample of six men and two women at least two years post incomplete C5 or C6 spinal cord injury.
Pullen, Povey and Grogan 2009	Women's decision making about attending cardiac rehabilitation classes	$n = 8$	Sample of five women who decided to participate in cardiac rehabilitation and three women who declined.
Glasscoe and Smith 2008	Experience of bringing up a child with cystic fibrosis	$n = 1$	An idiographic case report of one mother's experience taken from a corpus of interviews with four mothers who had one school age child with cystic fibrosis and at least one unaffected sibling.

* Figures derived from Academic Search Complete, January 2006 – December 2009, key words 'interpretative phenomenological analysis' in the abstract, self reported IPA study, results sifted for sample size from interview studies only.