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RESEARCH PAPER

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# The meanings of physiotherapy and exercise for people living with progressive cerebellar ataxia: an interpretative phenomenological analysis

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## ABSTRACT

**Purpose:** To understand the meanings of exercise and physiotherapy for people living with a progressive cerebellar ataxia.

**Method:** An interpretative phenomenological analysis was undertaken with 12 participants (4 women, 8 men) recruited via their membership of a national support group. Semistructured interviews were audio-recorded and transcribed. Data were analyzed using interpretivist methods.

**Results:** Two main themes were constructed. Firstly, participants highly valued building collaborative and supportive long-term therapeutic relationships with expert physiotherapists and were not necessarily looking to improve ataxia-related impairments. Secondly, self-devised exercise conferred multiple psychosocial benefits that were largely absent from physiotherapist-prescribed home exercise programs.

**Conclusion:** People living with ataxia recounted uniquely situated and contextualized understandings of exercise and physiotherapy that may differ significantly from the meaning of these terms to physiotherapists. Special attention should be given to patients' perspectives in order to provide services that are meaningful and valued by people living with ataxia.

## ARTICLE HISTORY

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## KEYWORDS

Physiotherapy; home exercise programs; self-selected exercise; ataxia; qualitative study

## ► IMPLICATIONS FOR REHABILITATION

- Physiotherapists should consider exploring the meaning of exercise and physiotherapy with individual patients to inform appropriate exercise prescription and advice.
- Poorly managed and inexpertly prescribed home exercise programs risk inadvertently disregarding the possible positive psychosocial effects of exercise participation and may prevent long-term engagement.
- To sustain long-term engagement prescribed exercises should be enjoyable, meaningful, satisfying and appropriately challenging.
- Physiotherapists should consider providing sustained, collaborative and flexible services.

## Introduction

The progressive cerebellar ataxias are a rare and complex group of ataxia-dominant, neurodegenerative disorders, characterized by incoordination of the limbs and trunk, dysarthric speech, dysphagia and oculomotor dysfunction [1]. No effective disease-modifying interventions are currently available [2]. Physiotherapy forms the cornerstone of the rehabilitation options offered to people living with ataxia [3]; however, high-quality evidence underpinning physiotherapy interventions for this condition is lacking [4–6]. Physiotherapists have described ataxia as a “difficult condition to treat” and report struggling to meet patients' expectations, and yet people living with a progressive ataxia may believe physiotherapy to be their “only hope” [7].

Little qualitative research has been undertaken to understand the perspectives of people living with a progressive ataxia, or their experience of physiotherapy. No studies have explored the meanings of exercise for people with ataxia. In what forms the most substantive qualitative inquiry, Daker-White et al. [7–9] explored the subjective experience of diagnosis, symptoms, medical management and physiotherapy services, with 38 people with a progressive cerebellar ataxia living in the Greater Manchester area in the northwest of England. Healthcare professionals, including

physiotherapists based in the same region, also participated in these studies. Consistent with results from an analysis of ataxia-specific internet discussion forums [10], people with ataxia described a slow and arduous path to diagnosis and encounters with clinicians who lacked specialist knowledge. Informants stressed the importance of being given a diagnosis but described a diagnosis of idiopathic ataxia as unhelpful. Daker-White et al. [7] reported patchy physiotherapy provision across the region which consisted of mainly National Health Service (NHS) community rehabilitation but also private practitioners funded by the NHS, or no NHS provision at all. Outpatient services were uncommon but were described as highly valued by those who accessed them. The service model of one appointment a week for 6 weeks followed by a home exercise program, was frequently encountered but criticized by people living with ataxia and by some specialist physiotherapists for its short-term approach. Most participants with ataxia expected “hands-on” care over a prolonged period but the meanings of this term were not explored [7]. The majority of participants (people with ataxia and physiotherapists) suggested that physiotherapy services should be staffed by clinicians with expert knowledge of ataxia, structured to offer long-term therapy, information, re-referral and support, and ways of measuring

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outcome that were meaningful both to patients and healthcare professionals. Those who reported most satisfaction with physiotherapy services were participants with ataxia who described long-standing, open-ended, on ongoing contact with specialist physiotherapists. These findings formed the basis of recommendations made by Daker-White et al. [7] for an “ideal neurological physiotherapy” service for people with a progressive ataxia.

While Daker-White et al. [7] drew attention to the perceived shortcomings of neurological physiotherapy in the management of progressive ataxia (at least in the UK), and the limitations of service provision from the perspective of individuals living with this condition, the sense-making underlying these findings, and the meanings participants inferred from their experiences were not deeply explored. Data collection and analysis were informed by a descriptive grounded theory approach and focused on generating broad general themes based on the Braun and Clarke [11] method of thematic analysis. Phenomenological approaches to qualitative research can complement other qualitative methods by offering a more in-depth, nuanced and detailed understanding of subjective sense-making that may further inform clinical practice [12]. If physiotherapy is regarded as the only hope for some people living with ataxia, it is important to understand what physiotherapy and “hands-on” therapy might mean to individuals in the context of living with this condition, and why short-term interventions and home exercise programs prescribed by physiotherapists may not be viewed favorably. Using interpretative phenomenological analysis (IPA) [13], this study aimed to explore and understand the meanings of physiotherapy, physiotherapy services and encounters with physiotherapists from the perspective of people living with a progressive cerebellar ataxia. It also aimed to understand the role of prescribed and self-initiated exercise, and the meanings of exercise in the context of living with ataxia. The findings of this enquiry may help physiotherapists to more effectively understand and address the concerns and priorities of people living with ataxia who seek their advice and support.

## Materials and methods

The methods underpinning IPA [13] were appropriate for exploring the meanings of physiotherapy and exercise which were expected to be complex, reflecting individual difference in illness experience and personal contexts, and individual encounters with physiotherapists and physiotherapy services. Researchers using IPA aim for a psychologically close reading of a participant’s account, and prioritize participants’ perspectives over and above what might already be considered known about the topic [13]. Meaning making and the development of research findings is an inductive and co-constructed process that involves the researcher making sense of and interpreting the perspectives offered by participants. In keeping with the tenets of IPA, a reflexive analysis is undertaken to examine and illustrate the impact of the researcher(s) on the research process and the findings [14].

### Recruitment

The study was formally approved by the research ethics committee of the host university. Ataxia UK (a charitable organization that offers support to its members and funds research into progressive cerebellar ataxia) facilitated a national recruitment strategy via conference presentations, distribution of information at local branch meetings, an advertisement in the *Ataxian* (the quarterly magazine for members) and via the Ataxia UK website. All those who were interested in participating were sent detailed

information by post or email. Questions were answered by telephone or email.

### Participants

Researchers using IPA usually recruit a small, homogenous, purposive sample for whom the research question is significant and meaningful [13,15]. Small samples allow in-depth analysis that does justice to the complexity of the rich, elaborated narratives offered by participants [13]. For the purposes of this study, participants were over 18 years of age and, in order to avoid the earliest stages of grief or shock, had been diagnosed with a progressive cerebellar ataxia for more than 6 months. Participants’ reports of their diagnosis were accepted without further medical confirmation. All participants had some experience of physiotherapy. A specified amount of physiotherapy or exercise was not stipulated as this may have closed off the opportunity to explore the meaning of physiotherapy and exercise in whatever form it had been experienced. Apart from requesting that potential participants were able to converse in English, no further criteria were used to define the sample.

Twenty-seven people with ataxia expressed an interest in participating in the study. Following provision of detailed information, 15 declined to participate or did not contact the principal investigator (EC) again. Following further telephone conversations and e-mail exchanges, 12 people with cerebellar ataxia agreed to participate. Although larger than commonly advocated, this remains an appropriate sample size for IPA [13].

### Data collection

Following formal consent procedures, semistructured interviews were conducted in a conversational style. Participants were asked to give background details about themselves, their symptoms and motives for taking part in the study. They were asked to describe what living with ataxia was like, how it had affected their day-to-day lives, recounting difficulties as well as positive experiences and significant relationships. In the second half of the interview, participants were asked to talk about physiotherapy, their encounters with physiotherapists, and physiotherapy services, and their experiences of exercise (whether physiotherapist-prescribed or self-initiated). Participants were invited to reflect upon what they had found useful and supportive as well as any negative experiences of physiotherapy. Their responses to these later topics provide the main data for this analysis although relevant material from elsewhere in their accounts is included. The relationship between interviewee and interviewer (EC) was collaborative and interdependent; both shared the responsibility for the direction the interview took but as far as possible participants’ perspectives, concerns and interests were privileged [16,17]. Salient topics were pursued as they emerged in participants’ accounts. According to preference, participants were interviewed in their own homes except for; Graham and Scott who chose to be interviewed together at the Ataxia UK offices, Jim who also chose to be interviewed at Ataxia UK, and Ted who preferred to be interviewed at work. All participants were recruited and interviewed by the principal researcher and have been given pseudonyms.

Interviews were recorded using a digital voice recorder. Each interview lasted approximately an hour (mean 67 min; range 53–104 min). As recommended by Smith et al. [13], data transcription was at the semantic level; recording all the words spoken, including false starts, pauses, laughter and any other significant events that occurred during the interview. Field notes were incorporated into a reflexive diary that recorded the principal

researcher's immediate thoughts about each interview and acted as a chronological means of mapping the development of these thoughts as data analysis progressed.

### Data analysis

Data analysis was undertaken by EC and followed published guidance [13,15]. Each transcript was analyzed independently before undertaking an across-case analysis. Each account was listened to several times to start the process of data immersion and where necessary to correct mis-transcription of technical words and indistinct articulations. Identifiable information was fully anonymised and pseudonyms, as noted earlier, were allocated to each participant. The transcript was closely read several times and an exploratory free textual analysis was undertaken. Initial note-taking focused on describing the things that mattered to participants in their account, and identifying and thinking about the contexts of their concerns and reported experiences. The next phase of the analysis involved an iterative re-reading and re-documenting of the text with the aim of mapping connections and patterns across exploratory notes. Candidate themes at a higher level of abstraction than the initial impressions were then identified. Themes captured and reflected a deep understanding of those parts of a participant's life that had taken on a particular meaning, in this case, for example, the meaning of physiotherapy or exercise. The penultimate stage of analysis connected themes across the data and similar themes were clustered together (subordinate themes). Superordinate themes which best captured the subordinate themes were finally developed and identified. The final analysis aimed to describe not only how participants perceived their experiences but also, at a deeper level of interpretation in keeping with IPA, looked for implicit meanings that participants were unlikely to have foreseen themselves [15]. Themes were created based on their ability to illuminate meaningful experiences rather than on their frequency or prevalence within the data [15].

Consistent with the commitment to understanding the unique perspectives of participants, each account in the paired interview (Scott and Graham) was parsed and analyzed individually (as described above), focusing primarily on the intrapersonal data rather than the interpersonal data. Subordinate and superordinate themes were separately developed for each participant. However, with reference to Smith [18], the accounts were analyzed 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 amplified or developed ideas but also demonstrated experiential divergence as would be expected in these highly personal contextualized accounts.

The across-case analysis involved overt referral to all cases looking for differences as well as similarities in experiences, identifying patterns, re-working and renaming themes as a deeper understanding of the data developed [13]. The overarching themes reported here encapsulated the main ways in which physiotherapy, physiotherapy services and encounters with physiotherapists, and physical exercise were understood.

Throughout the analytic process, a critical reflexive approach toward data construction and analysis was undertaken. The principal investigator's previous experience as a specialist physiotherapist in neurological rehabilitation was also taken into account. Two coresearchers, one a health psychologist (FR), the other a physiotherapist (SN), carefully interrogated candidate and final themes, and challenged assumptions and interpretations that required further justification or deeper analysis.

## Results

### Contextualizing the sample

Participants lived in England (widespread locations) and were aged between 31 and 73 years. Of the 12 participants four were women. All participants had been diagnosed with a progressive ataxia. Not all participants had a definitive diagnosis which is not unusual [19]. Time since symptom onset ranged from a minimum of one year to a maximum of 23 years. Most participants had lived with symptoms, if not a definitive diagnosis, for over 10 years, some for much longer. Five participants lived alone, six lived with their partner, four of whom also lived with dependent children. One participant, Harry, lived at home with his parents. All participants lived independently except for Bill whose wife was his full-time carer. Demographic information is presented in Table 1.

Two interconnected main themes were inferred from the analysis. The first explores participants' experiences of physiotherapy, physiotherapists and physiotherapy services, the second explores the subjective meaning of exercise, both physio-prescribed and self-initiated physical exercise.

### Theme 1 Connecting with knowledgeable others through physiotherapy: 'you're not dealing with ataxia on your own; somebody else is actually taking a bit of an interest' (Graham)

Participants' accounts portrayed both positive and negative experiences of physiotherapy. The majority of participants looked to forge long-term partnerships with physiotherapists but regretted that this kind of therapeutic alliance was rarely encountered in practice. Most participants described making frequent but frustrated attempts to engage with physiotherapists and physiotherapy services, and several participants perceived that physiotherapists lacked the necessary expertise to work effectively with people living with a progressive ataxia. Deeper analysis revealed that physiotherapy held a symbolic meaning in the lived experience of each participant, and this meaning was shaped by the particular contexts and healthcare experiences they had each encountered.

Harry's account of physiotherapy was the most positive of all participants. Unlike other participants, Harry reported that he had built a very good rapport with his NHS physiotherapist over many years:

*Harry: 'I've been seeing [name of physiotherapist] for years... poor girl, she must be sick of me [...] If I need to see her I can go to see her anytime. [...] I've got her E-mail. 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 highly valued by Harry. Long-term continuity of care seemed important, not simply the existence of an ongoing service but perhaps more importantly the same physiotherapist. This physiotherapist represented a dependable and trustworthy figure for Harry, particularly so when he perceived himself abandoned by other services and clinicians in the past (a common experience for the majority of participants):

*'... my physio never stopped ... physio stayed and everything else disappeared; occupational therapy, neurologists, cardiologists, all of those other people, stopped getting in touch.'*

Furthermore, Harry's physiotherapist seemed to be able to offer a person-centred service which met 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 [well]... they will try and have me back if I deteriorate, that's the worst time of year for me. Cos I get bad when it's overcast and I just like ... I don't want to go out, you know. Don't want no exercise.'*

Table 1. Participant demographic information.

Anonymised name (marital status)	Age	Type of ataxia	Time since onset	Occupation
Ted (married)	Early 40s	Late onset Friedreich's ataxia	About a year	Financial services
Harry (single)	Early 30s	Friedreich's ataxia (diagnosed in adulthood)	Since late childhood	Software consultant
Joan (divorced)	Early 70s	Working diagnosis of episodic ataxia	Uncertain but not more than 15 years	Retired civil servant
Susan (married)	Mid 60s	Cerebellar degeneration	Uncertain but not more than 15 years	Retired housewife
Scott (single)	Early 40s	Cerebellar ataxia, no definitive diagnosis	6 years	Retired (ill health)
Graham (single)	Early 40s	Cerebellar ataxia, no definitive diagnosis	Many years but more significant symptoms over last decade	Unemployed (looking for work)
Hugh (married)	Early 50s	SCA 6	Many years, diagnosed about 10 years	Administrator
Stella (lives alone)	Mid 50s	Cerebellar ataxia, no definitive diagnosis	Uncertain but not more than 15 years	Retired
Bill (married)	Late 50s	Cerebellar ataxia, no definitive diagnosis	Symptoms for many years, diagnosed 13 years	Retired (ill health)
Toby (married)	Mid 50s	Idiopathic cerebellar ataxia	4 years	Retired (ill health)
Julia (lives alone)	Late 60s	SCA 6	22 years	Retired
Jim (married)	Late 40s	Cerebellar ataxia	23 years	Administrative manager

*'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.'*

The above quotations suggest that physiotherapy not only addressed Harry's physical impairments but also symbolized the potential for renewal, and new prospects for living. Physiotherapy also perhaps offered a means to circumvent the downward spiral of inactivity and despondency he described. Harry's experiences of physiotherapy seemed uniquely situated as none of the other participants described a comparable level of dependability, connectedness and trust with a particular physiotherapist.

Julia's experiences of physiotherapy were also generally positive. For Julia, physiotherapy symbolized a valuable resource for 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.'*

It seemed that the majority of participants not only looked to physiotherapists as a resource for information and advice, but also to establish and maintain a sense of connection with an informed other. Yet for most participants, this sort of relationship and expertise seemed beyond the capacity of the physiotherapy services they encountered. Short interventions ranging from one-off appointments to sessions once a week for six weeks were usually followed by the prescription of home exercises. These were easily forgotten or put aside. Susan's account exemplified the difficulties expressed by some participants with reference to the prescription of a home exercise program:

*'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.'*

Not only was Susan unable to do the home program, her prescribed exercises seemed to emphasize rather than diminish her physical difficulties as well as exacerbate her fatigue. She also

described her physiotherapist as concerned with measuring improvement which meant very little to Susan:

*Susan: 'She [the physiotherapist] 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.'*

From Susan's perspective, the physiotherapy that she experienced was not tailored to her as an individual, and measuring improvement did not make sense to Susan in the context of living with a progressive condition. Susan also 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:

*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 looked for 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. She described a rigid application of a particular model of service and an authoritarian orientation to her care which gave prominence to the physiotherapist's expert status. Susan had previously emphasized her commitment to exercise, explaining that in the absence of other advice she had brought a treadmill to try to strengthen her legs. For Susan, physiotherapy symbolized possibilities for ongoing support and close involvement with a knowledgeable other but in her experience, physiotherapists seemed rather remote and disengaged, and differed significantly in what they could offer from what she had hoped.

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.'*

Stella described having an open-ended access to physiotherapy where she carried the responsibility of judging if and when she needed more help. This approach may have been well-meaning, in terms of having an "open door policy", but for Stella it seemed to signify an additional and perhaps unwelcome burden to cope with, and may have given an unintentional but unfortunate impression that in every practical sense she had been sent away to manage on her own. Stella's experience of this type of self-referral system differed significantly from Harry's more positive experience. Harry and his physiotherapist had built an effective, close working relationship that had been forged over a long period of time whereas Stella (and Susan) described short-term encounters with different services and personnel. Under these circumstances it is perhaps more difficult to develop the same degree of trust and respect that underpinned Harry's experience. These accounts suggest that short-term services may not necessarily be problematic in themselves but significant investment in building effective working relationships over time may be required if these services are to be considered successful and beneficial by the people who access them. Graham, who generally spoke of physiotherapy in positive terms, offered further insight:

*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 also 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 empathize seemed to be highly valued by participants. Nonetheless, 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 favorably of a physiotherapist-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. Secondly, 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. However, for the majority of participants, physiotherapists lacked the flexibility or capacity to admit and respond to the importance that participants placed on being involved in decision-making about their care, and were unable to forge or sustain the personal relationships and therapeutic alliances that participants seemed to value. Only Stella and Jim talked about exercise-on-prescription. Both felt that they had to persuade their general practitioner to refer them to this service ("There's a GP referral scheme to a gym in our area and I sort of conned myself onto that" Jim), and, again regretted the limitations of being offered a short-term program. Stella found gym membership expensive and

therefore stopped attending when her prescription ended, whereas Jim later joined a gym sometime after he had completed his prescribed course.

Several participants also criticized physiotherapists for not having a strong understanding of ataxia, and in lacking knowledge about effective treatments:

*Harry: '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.'*

Despite Harry's positive experiences of partnership-working, he seemed horrified that there was no 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 and highlighted inexpert practice lacking a strong evidence base:

*Bill: 'I've got little kind of confidence in it [physiotherapy] really [...] If I know more about it than they [physiotherapists] do, there's something wrong there.'*

*Stella: 'They just don't have the staff I suppose and the knowledge of my particular problem [...] I felt they had not much idea about my condition or how to deal with it.'*

*Julia: 'The physio couldn't separate me from MS in her mind.'*

In summary, participants were not looking for a cure, or necessarily an improvement in physical impairment but to connect with a knowledgeable, thoughtful professional who would take the time to carefully listen, and who could offer long-term collaboration, sound advice and support. Participants therefore seemed to place importance on physiotherapists who could help maintain hope and maximize day-to-day living. However, physiotherapists and physiotherapy services were for the most part perceived as unable to fulfill these hopes or meet participants' expectations. In the absence of a strong evidence base, physiotherapists may underestimate the potential value and positive role they may have in helping people to live with ataxia, a role that necessarily extends beyond straightforward exercise prescription, and management of impairment.

### **Theme 2 Physical exercise as a means of sustaining a positive sense of self: 'it does make you feel good and you've got an awful lot of control over things' (Scott)**

All participants had taken part in a wide variety of physical exercise since being diagnosed with a progressive cerebellar ataxia (Table 2). The type of exercise was selected by the participant and not prescribed by a physiotherapist, except for specific home exercise programs. 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 about attending to the impaired body. This theme looks at the ways in which participants described exercise and the meaning of exercise-based activities.

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.'*

Table 2. Physical exercise undertaken by participants.

Activity	Participants
Home exercise program – prescribed by a physiotherapist	Toby, Stella, Susan, (Bill)
Home exercise program – self-devised or adapted	Julia, Susan, Harry, Joan, (Hugh)
Swimming	Stella, Toby, (Ted), (Hugh)
Gym	Jim, Scott, (Ted)
'Exercise on prescription' – gym	(Stella), (Jim)
Yoga class	Joan
Pilates class	Joan
General exercise class	Julia
Nonmotorized air sport	Harry
Adapted cycling	Harry
Water sport	Scott
Team sport	Graham
Dancing	(Joan)
Rambling, hiking	(Joan)
Tai Chi	(Joan)
Jogging (outside)	(Stella)
Golf	Stella

(Name in brackets = these participants were no longer doing this activity at the time of interview).

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 (babysitting), it also seemed to provide her with a sense of achievement. She recounted 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 focused on maintaining her grand-mothering role, other factors also helped to sustain the regular practice required in order to hold onto this role. From a social perspective other residents of her apartment block 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. The successful completion of this daily task perhaps provided an additional sense of achievement, motivation and positive feedback.

Julia also described how she had devised her own exercise program. It was put together by Julia but members of her family had helped her by measuring the distances involved, calculating the number of steps, accessing the music that Julia had chosen to accompany the exercise and uploading it for her. Julia's exercise routine was therefore portrayed as a family concern and represented 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 program 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."* It is interesting here that Julia does her physiotherapy *"in private."* This suggested perhaps that Julia believed there might be something embarrassing or uncomfortable about doing these stretches in public. While 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 herself 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 not only 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 this theme demonstrates, exercise contributed in several complex ways to preserving a positive sense of self for other participants in the study.

Toby, for example, swam regularly 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 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 of living with a progressive condition. Toby also emphasized the value he placed on having a sense of purpose (*"It's giving me a reason to get up in the morning"*) and he derived benefit from the commitment to a particular routine, perhaps in similar ways to Julia's daily circuit of her residential complex.

Several participants spoke of the importance of exercise as a means of doing something positive in the face of living with a progressive and incurable condition. 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 physical 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."* While reflecting upon the psychological benefits of exercise, these participants might also have been resisting passive formulations of the self, resisting a view that they had simply given into whatever ataxia wrought in their lives: *"it's so easy to sit at home, watch telly and ..., wondering about the next episode of 'EastEnders'"* (Harry). These participants perhaps

saw exercise as a means of standing firm against a negative sense of self:

*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. 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 the meaning of 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, and capability moving forward in time (underlined in the text), 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 their ataxia had not improved 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 approach possibly helped Scott develop a positive relationship with his ataxia, and in this way it was not some abstract concept or unknowable thing that he had no control over. Similarly, as 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.'*

*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.'*

Scott seemed to suggest that he felt stuck at home and needed strong incentives ("*controllers*") to get out of the house, and exercise seemed to provide this sort of motivation. Graham perhaps wanted the researcher to understand that having a disability can cause social isolation. He did not directly make this claim for himself (there may be a hint of self-preservation here in the context of the interview) but in a general sense. However, he made it clear that he was doing things in his life to avoid isolation or loneliness, and in this sense, he emphasized his resourcefulness, and self-determination. Also, his sport is absorbing, it is something he has to think about, and concentrating on the sport may give him some sort of respite from thinking about ataxia, or dwelling on its more negative effects. Scott and Graham, both conveyed a sense that they were achieving something by doing these activities, and that these were accomplishments the researcher would recognize and respect. Scott had passed his "*one star*" and described himself as "*gradually improving,*" and Graham seemed 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 they experienced in living with progressive ataxia. Furthermore, these activities marked a return to sports that both Scott and Graham used to do before their diagnoses, and may be seen as a connection to their pre-ataxia self, 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 described a type of nonmotorised air sport as giving 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 was also concerned with the ways in which he (as did other 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 fulfill 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.

Participants' accounts suggested that it would be a mistake to understand their engagement in physical activity 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 activities and authentic involvement with others; health promotion perhaps in the broadest of senses. Physiotherapist-prescribed exercise formed a small focus here, most were self-discovered types of activities and sports. 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 psychosocial concerns, and their contribution to sustaining a positive sense of self varied for each participant.

## Discussion

Daker-White et al. [7] reported that people living with ataxia may view physiotherapy as their “only hope.” These authors also highlighted that patients expected “hands on” therapy [7], and criticized physiotherapists for delivering short-term services followed by provision of a home exercise program. Our study offers further insight and a deeper understanding of these perspectives. For participants in this study, the meanings of physiotherapy and exercise were found to be complex, multifaceted, and personally contextualized. Although it might be assumed that the meanings of physiotherapy and exercise would be closely linked, this study revealed that, for most participants, the meanings of physiotherapy differed significantly from those of exercise, and prescribed home exercises. These findings might be considered as surprising new knowledge.

Participants who described positive encounters with physiotherapists and physiotherapy services identified a strong psychosocial dimension to their positive appraisals. A similar emphasis was also articulated by those who described what they had hoped to experience from physiotherapy. Participants’ accounts did not suggest that they were looking for a cure, or necessarily impairment-level intervention. Participants looked for and valued ongoing, close involvement and connectedness with a trusted, dependable and knowledgeable professional who could listen, give expert advice, practical support, and equal partnership in planning, organizing, developing and monitoring care. Physiotherapy symbolized possibilities for revitalization, collaboration, off-loading, and knowledge sharing and acquisition. The degree and extent to which each of these components of care were emphasized and discussed depended upon personal contexts and experience. “Hands on” therapy might therefore be best understood not in the literal sense, but as a holistic practice provided by physiotherapists who are closely and actively engaged with patients, and who fully participate in the design and long-term management of their care. Unfortunately, in the experience of participants, it seemed that physiotherapists were not always able or in a position to fulfill or sustain these hoped-for roles, or to recognize and act on the level of expertise and resourcefulness participants themselves had attained. Rather than prioritizing and engaging with a person’s preferences and interests, the perceptions of most participants in the present study suggested that, in their experience, physiotherapists held onto biomedical views of the body, and, in particular, perhaps in light of the limited evidence base in this field, a view where physiotherapy was constituted simply as repair or maintenance work for an impaired body.

Our findings also contextualize the findings of Daker-White et al. [7] with respect to the criticism of short-term packages of care and structured exercise prescription. In the present study, prescribed home exercise programs were perceived to work well where programs had been jointly developed, regularly monitored and when psychological benefits such as a sense of control and

agency were also conferred. However, home exercise programs were negatively appraised when they were perceived to be ineptly prescribed and poorly monitored, if they were perceived to offer no tangible psychosocial benefits, when they increased fatigue, and heightened the salience of ataxia in participants’ lives. Furthermore, and perhaps contrary to expectations, prescribed home programs regrettably had the potential, in some cases, to diminish the sense of self and reinforce constructions of the self as fragile and infirm. For some participants, six week blocks of treatment created a similarly unfortunate sense of being sent away to manage ataxia by themselves and without easy access to expert support. However, positive appraisals of these short-term packages of care were evident in a minority of participants’ accounts. Analysis showed that this type of service provision was deemed beneficial when it was underpinned by long-term and continuing therapeutic relationships, and combined with collaborative decision-making. Nonetheless, the majority of participants had invested a meaning and significance into their understanding of physiotherapy, service provision and home exercise prescription that they believed for the most part physiotherapists were unable to appreciate or consider.

In comparison to prescribed home exercise programs, self-selected exercise conferred a number of social, emotional and psychological benefits. Self-selected exercise held a personal significance and meaning for each participant that helped to sustain commitment and motivation. Preferred exercise programs also worked to maintain valued roles and activities, to overcome the effects of social discrimination, to sustain social networks, and to preserve biographical continuity, a positive sense of self, and the sense of being an active person. Self-chosen exercise also curtailed disability-related distress, and reduced the salience of ataxia in participants’ lives. Several participants set themselves challenging goals as part of their chosen exercise, and derived enjoyment, satisfaction, and a sense of achievement from pursuing these goals. When understood from a phenomenological perspective, in the context of participants’ lived experience, participation in self-selected exercise symbolized a means not to cure ataxia but to better cope with its effects. Self-selected exercise took the focus off the ataxic body and gave salience to the person rather than the condition. Taking part in activities such as non-motorised air sport, swimming, team sports, water sports, self-developed exercises, and exercise classes such as Pilates, may have helped resist the negative labeling often associated with long-term progressive conditions, and maintained a sense of identity and self-esteem that was not overshadowed by the effects of ataxia.

A significant body of research supports the view that for people living with a variety of long-term conditions, exercise and physical activity confer positive psychosocial effects and wide-ranging therapeutic benefits, such as rebuilding self-confidence, de-emphasizing physical impairment and disability, regaining a sense of control over physical health and emotional well-being, preserving self-identity, limiting illness-related psychological distress and fostering a sense of belonging by connecting with others [20–25]. Significant psychosocial benefits have been reported even when it was uncertain whether exercise had a direct (impairment level) effect [25]. Physical activities that focus on enjoyable experiences and developing social support may also have a positive impact on quality of life [26].

Our study also suggests that activities, which offer an added sense of challenge, enjoyment, achievement and satisfaction, may also sustain the motivation to continue to exercise and, by rendering ill health as less of a “master status,” may diminish the relevance of physical impairment on the sense of self. Similarly, Mulligan et al. [27] reported that participation in preferred but

challenging activities conferred intense feelings of satisfaction, empowerment and fulfillment which became self-motivating for people living with a variety of neurological conditions. Parallels can be drawn with Scott's participation in water sports and Graham's team sport involvement, as well as Julia's self-devised home exercise program, and Toby's swimming. All of these were self-chosen activities which offered considerable physical challenges but also personally meaningful rewards, adding to a sense of achievement and satisfaction, and the motivation to carry on. Conversely, Mulligan et al. [27] also reported that prescribed exercise or exercise provided in a way that did not match individuals' preferences (e.g. a 6 week on, 6 week off rotation, similar to service models described by participants in the present study) as unfulfilling, unsatisfying and frustrating. This view also resonates with some of the views of physiotherapy described by participants in our study. Home exercises that only attend to bodily symptoms, and measure impairment level outcomes strictly in terms of improvement or maintenance, also seem narrowly conceived and inadequate with respect to the potential benefits of exercise identified by participants in the present study. Salmon and Young [28] have argued that poorly managed partnership working and promotion of self-management strategies that are not underpinned by genuinely collaborative practices that take account of patients' vulnerability, risk turning patients into agents managing their own suffering. We also found that poorly conceived home exercise programs, with inadequate monitoring and limited access to expert physiotherapists, may also add to the burden of living with a progressive ataxia, and in turn provoke feelings of disappointment, disempowerment and demotivation.

An approach to physical activity that focusses on reducing sedentary time and increasing light-intensity physical activity has been advocated as a potentially potent means of improving metabolic health for people with mobility disabilities [29]. Participants in the present study perceived physiotherapists as focused on prescribing impairment-level, home-based exercises that were perhaps consistent with this important model of health promotion, and yet the value participants placed on undertaking other forms of activity and exercise was perhaps overlooked by their physiotherapists. We would suggest that the two approaches are not incompatible. Rather than facing a disconnect, physiotherapists are well placed to work with people with ataxia to not only support their participation in personally meaningful activities and exercises, but also to collaborate on working out the best means of adopting a health promoting, whole-of-day approach to physical activity. Our findings are also consistent with arguments that "exercise prescribed as medicine," such as prescribed home exercise programs, may, if poorly managed, inadvertently minimize the experiential rewards of exercise, such as social engagement, self-development and enjoyment that would normally help to sustain long-term participation [30]. Physiotherapists should therefore consider promoting activities that appeal to intrinsic motivations, such as doing exercise for its inherent satisfaction and enjoyment, rather than for reasons that are simply about improving bodily function or performance. However, our findings also suggest that multiple and interacting psychosocial constructs underpin sustained engagement in exercise for people living with a progressive ataxia. These findings suggest that physiotherapist may have much to learn by understanding exercise motivation from the perspective of self-determination theory [30]. This approach would require perhaps novel ways of evidencing outcomes and may offer a considerable challenge to NHS physiotherapists and those who have to similarly justify and account for services.

In a situation where there is very limited evidence to guide physiotherapy practice [4-6] and where further research is

urgently required, an impairment-focused, home-based approach to exercise prescription may overlook the potential benefits that may be achieved from taking a more pluralistic stance towards exercise. Our findings suggest that exercise and physiotherapy can make a positive contribution to living with ataxia. However, negative appraisals of physiotherapy and home exercise programs were described by participants when the complex and highly contextualized meaning of exercise and physiotherapy had not been adequately appreciated or considered. These findings should encourage physiotherapists to carefully and actively explore the meaning of exercise and physiotherapy at an individual level with people living with a progressive ataxia. Only by doing so will physiotherapists be able to develop satisfying and enjoyable approaches to sustaining physical activity for individuals living with ataxia which have the capacity to improve quality of life whilst simultaneously coping with bodily impairment.

Daker-White et al. [7] identified nine features of an ideal physiotherapy service for people living with a progressive ataxia, our findings add further nuance to this model. We suggest that physiotherapy and exercise prescription should respect the expertise and resourcefulness of people living with ataxia, seek to understand the meaning of exercise in the context of patients' everyday lives, and focus on the achievement of self-directed goals through doing enjoyable, challenging and meaningful activities. At the same time, advice and on-going support should be offered in a flexible and responsive manner. We argue that outcomes should comprise patient-centered and quality of life measures that have meaning in the everyday lives of people living with a progressive ataxia. The approach we advocate would operate at a local, personal, and relational level, a human scale based on an understanding of the phenomenological dimensions of long-term illness. We argue that these constituents of care should not be seen as unachievable ideals but as fundamental facets of a human-centered practice, well within reach of practitioners in the UK and elsewhere.

System-wide changes to health service provision are needed to make enduring and sustainable improvements to the care of people living with long-term conditions [31]. The barriers to providing sustained, collaborative and flexible services extend well beyond the control of physiotherapists, but physiotherapists retain a key role in developing responsive patient-centered services, as well as advocating for better proactive health care for many potentially vulnerable members of our society with long-term neurological conditions. Exercise on prescription programs have the potential to build self-efficacy for exercise for people with neurological conditions but further research is required to understand the best means of prescribing and providing this service, and to maximize health as well as psychological and social outcomes [32]. Further research that explores how physiotherapists conceptualize exercise, home exercise programs and their role in working with people living with ataxia would also be helpful. Discursive approaches to understanding encounters between physiotherapists and people living with ataxia may provide a useful method of enquiry.

In acknowledging the limitations of this study, the following points should be considered. Recruitment of research volunteers through membership organizations can raise concerns about the characteristics of participants. Kroll et al. [33] argued that members of organizations 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 organizations. 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, for example, those from a minority ethnic background, would offer similar or different interpretations of living with ataxia. Also, the majority of participants in this study were able to walk at least short distances indoors, and lived with little or no additional support from agencies or services. Exercise participation may have required adjustment to equipment and other adaptations but participants were for the most part able to take part in activities without significant physical support. The findings would therefore not necessarily have resonance for people with more severe impairments, or those receiving support to undertake daily living activities. However, a few participants were more severely impaired but with help were able to participate in their chosen activities. 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. 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. Finally, compared with countries where health services are not free at the point of access, NHS provision is enabling in some ways, and yet the very availability of NHS services may increase expectations about access which are then unable to be met. It is not known therefore whether the positive or negative experiences reported here would be similar in other countries or not.

The findings of this study cannot be generalized in a straight forward way. The accounts were co-constructed and framed by both the researchers' and participants' personal, cultural, historical and social contexts. The findings are therefore local, provisional, and open to further interpretation [13]. IPA does not aim to produce objective or definitive findings and does not make any claims about being able to directly access experience, only to access and analyze an account of an experience as the participant makes sense of it during the interview [13,15]. The resulting narrative should be revealing, important and of value, not because it lays bare the essence of a particular phenomenon, but because the stories people tell about their lives say something about their constructed but uniquely situated identities, and, by doing so, provide insight into what otherwise may be hidden or overlooked in day-to-day life [34] or healthcare practice. The meanings derived from the analysis are context-dependent and are not meant to create broadly applicable knowledge. However, the context of this study has been described in detail so that readers may interrogate the findings and arguments presented here and, through a process of theoretical generalizability [13], explore assumptions about their own practice and assess the evidence presented in relation to their existing professional and experiential knowledge.

## Conclusions

This study has emphasized the importance of understanding physiotherapy and exercise for people with progressive ataxia from a phenomenological perspective. Physiotherapy and exercise held different meanings for participants in this study, and these meanings were significantly contextualized. Physiotherapy and prescribed home exercise programs were understood to be primarily concerned with the impaired body, and for the most part, did not address the psychosocial challenges of living with a progressive ataxia that were considered highly relevant to

participants in this study. Self-directed exercise and activities conferred multiple benefits which helped participants to sustain psychological well-being and to reduce the salience of ataxia in their everyday lives. Genuine collaboration between physiotherapists and people living with ataxia, underpinned by a contextualized understanding of life with ataxia, would go some way towards developing physiotherapy practice and service delivery in ways that would be valued by people living with ataxia. These findings may provoke physiotherapists working with people living with a progressive ataxia to re-evaluate the meaning of physiotherapy and home exercise programs, and the ways in which physiotherapy services are provided from the patient perspective. Furthermore, physiotherapists might consider supporting and encouraging people living with ataxia to undertake self-chosen exercise programs and/or to participate in sports and activities that are meaningful to individuals in the contexts of their own lives, even in the absence of direct impairment level effects.

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