

## **Contemporary physiotherapy practice for people with ataxia: the perspectives of clients and physiotherapists**

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The aims of this project were to record physiotherapy practice for people with ataxia, and explore the experiences of physiotherapists and people living with ataxia in order to identify areas for improvement and topics for further investigation towards improving physiotherapy strategies and services. 22 specialist neurophysiotherapists took part through four focus groups, and 12 people with cerebellar ataxia were interviewed individually or in pairs. The people with ataxia ranged in age from early 30s to early 70s, and had all experienced physiotherapy mostly as outpatients or in a community setting, rather than as inpatients. The physiotherapists all had at least three years experience of working with patients with cerebellar ataxia.

### **Findings**

The majority of physiotherapists described ataxia as a frustrating and difficult condition to treat. Several reasons emerged from the analysis of the focus group data to account for these views. The physiotherapists reported limited research evidence to guide physiotherapy practice, which was compounded by a limited experience in treating people with cerebellar ataxia when compared to conditions such as multiple sclerosis and stroke. Furthermore the contribution of the cerebellum to movement control was regarded as complex which in turn led to difficulty in the assessment and therefore treatment of the underlying movement problem. Participants with ataxia also recounted experiences where it seemed their physiotherapist had a limited understanding of their condition and treated them as if they had a stroke or multiple sclerosis, therefore aligning their experience with that reported by the physiotherapists.

Perhaps encouragingly, all the physiotherapists who participated in this study demonstrated interest and enthusiasm for learning more about ataxia and for improving their practice. Two groups reported increasing numbers of referrals of patients with ataxia for physiotherapy and this was welcomed as an opportunity for learning and development of practice.

Despite acknowledging the limited evidence base available to guide physiotherapy practice for ataxia, several similar approaches to treatment emerged across all groups and although the physiotherapists were uncertain about the underlying efficacy of their treatment, they gave a reasoned and pragmatic account of the interventions they most commonly provided for patients with ataxia. There was a consensus about the most frequently used treatments, that, whilst it may not be representative of all physiotherapy treatments, points towards those interventions that should perhaps be prioritised for further research including; core stability exercises, the role of specific strengthening programmes, aerobic exercise and home exercise programmes.

Both groups of participants (physiotherapists and people with ataxia) recounted frustrations with service provision and responsiveness of services. It was not uncommon for people with ataxia to comment about resource and funding pressures influencing services, similarly some physiotherapists described not having enough time with patients and being constrained by funding issues. It seemed that services were dependent on location which affected referral, access and duration of treatment and follow up services. A few participants with ataxia

recounted positive experiences of physiotherapy and physiotherapy services lending support to the view that service provision across the country is patchy. Further research is required to investigate service provision from a broader perspective but the experience described in this study is that people with ataxia have difficulty accessing specialist services and, given the distribution of people with ataxia across the country, innovative methods may be required to help resolve this problem.

In summary, both strengths and limitations of physiotherapy and physiotherapy services were recounted by both sets of participants in this study. There was a consensus about the most pressing issues for further research across the two groups which can be briefly summarised as the further development of the evidence base for physiotherapy for ataxia and further development of services that are responsive and easy to access.

The physiotherapists who participated in this study seemed to focus a lot on *progress*; for example they spoke of needing sufficient time with patients to make meaningful changes; improving the vestibular ocular reflex (the reflex that stabilises images on the retina during eye movement thus preserving the image in the centre of the visual field), upper limb coordination, balance, core stability. Whilst an approach to treatment that is focussed on recovery or improvement may be appropriate for people following stroke or those recovering from a multiple sclerosis relapse, it might not be such a useful model of physiotherapy for people who have one of the progressive forms of the cerebellar ataxias. The approach to treatment described by the physiotherapists in this study may reflect their experience of treating ataxia as a recovering condition. Some useful insights have been gained that may also be beneficial for people with spinocerebellar ataxia or other types of the progressive ataxias but further research is required to determine the efficacy of these interventions.

However, the participants with ataxia in this study were not generally seeking advice from physiotherapists about how to cure or recover from their condition. The participants in this study regarded physiotherapy and exercise almost as the same thing - a means of preserving function and maintaining strength to prolong participation in meaningful activities. Further work is required, but the accounts from physiotherapists and participants with ataxia seemed to suggest quite a biomedical approach to physiotherapy, highlighting concerns with interventions and outcomes. These impressions from the data may be a function of the questions asked in the focus groups or the short hand used by professional groups when talking amongst themselves, however it is understood that the biomedical model itself can frustrate and disappoint professionals when confronting a patient with an *incurable* illness. There may be a mismatch between physiotherapists who are seeking to 'do' things to people with ataxia and the people with ataxia who are (on the whole) seeking out resources, and trying to maintain their mobility, activities and interests through the development of self-management strategies.

A further tension that may influence this issue is that all the participants with ataxia in this study were treated as outpatients or in the community. Inpatient experience was described in terms of a hospital admission following a fall or for investigations to further a diagnosis. Anecdotal evidence, from other sources and not drawn from the findings of this study, suggests that physiotherapists may, in some cases, be taking on the role of occupational therapists in the community. If this is the case, it could be hypothesised that the role of OTs who traditionally work by helping people to maintain meaningful occupations rather than from

a biomedical perspective may be falling to physiotherapists who may be underprepared to assume this responsibility.

Clearly, further investigation of these issues is necessary to determine whether this is in fact the case and whether a mismatch of roles is a significant factor influencing the experience and effectiveness of physiotherapy for people with ataxia.

### **The experience of people affected by ataxia**

Several consensual themes about the experience of living with ataxia emerged from the majority of the accounts; two of these were concerned with the symptoms of ataxia that are perhaps under reported in the literature, namely fatigue and difficulty with divided attention. The other two themes were quite different; one recounted the struggle and fight experienced by most participants when dealing with certain aspects of the National Health Service, particularly at the time of diagnosis but also in terms of trying to maintain contact with key personnel such as consultants and physiotherapists; the other theme was concerned with fighting back and taking control, for example by taking an active stand to improve referral to other services, requesting further investigations, and by managing symptoms and participating in valued activities and interests.

Fatigue emerged as a significant symptom for most participants in the study. Rather than tiredness it was usually described in terms of a rapidly depleting energy supply resulting in extreme fatigue and an exacerbation of other ataxic symptoms. Most participants had developed or were trying to develop strategies to manage this aspect of living with ataxia which often restricted or at least curtailed participation in valued activities. Several factors may contribute to the experience of fatigue and at least one of these may be related to the concentration required to undertake everyday activities that are normally controlled subconsciously. However, further research would be useful to identify other factors that may be amenable to self-management strategies that would help to control this condition.

Several participants described problems carrying out activities under conditions that demanded divided attention. The role of the cerebellum in cognitive processing seems to be contested in the literature and other issues, such as fatigue, may contribute to the problem of attention described by the participants in this study. Further research would be useful to investigate this problem and to provide information to people with ataxia, physiotherapists and other healthcare professionals about how it might be best managed.

One of the major themes that seemed to apply to most but not all participants was that, at some point in their journey with ataxia, participants had struggled to access information or healthcare services at critical times, usually during the process of diagnosis (which was often protracted) or following an acute episode such as a fall. For several participants these experiences were in the less recent past and therefore systems and processes may have changed. Furthermore, Ataxia UK has recently undertaken research specifically to look at the process of diagnosis and important findings may emerge that may lead to the development of better client-centred services for the assessment and diagnosis of the progressive ataxias. However, as outlined above, access to the specialist services valued by people with ataxia remains a problem and requires further investigation.

All participants adopted one or more strategies to help manage their symptoms and to maintain their participation in the activities they most valued. The majority of participants described being involved in some sort of exercise and several had adapted or continued with

rewarding or enjoyable activities they had either taken up prior to the onset of symptoms and before symptom progression. The reasons for this were complex; it seems that these activities provided participants with resources in the battle against the effects of the condition, for example helping to maintain a sense of identity and biographical continuity. They may also have preserved social contact and in some cases helped to disrupt the vicious circles that increased the risk of depression.

Several participants experienced stigma as a consequence of living with ataxia. Only one participant reported having the opportunity to formally address issues of stigma and oppression associated with disability.

Contemporary perspectives of disability and society are often considered the preserve of academics and are described in text books that are perhaps not readily available for people outside academic institutions. However, it seems that other resources are available that might help combat stigma. For example a participant in his late fifties described the comfort and support he gained from listening to the BBC Ouch! Podcast.

The experience of stigma may be under reported in the literature that is available to the general public and although further research may be necessary it would seem important that people with ataxia have access to information that can help them deal with stigma and oppression. The BBC Ouch! podcast may be a useful model to develop as a forum for discussion in addition to the more formal structures in place such as work based disability training programmes which are obviously limited to those who are employed.

### **Areas for further research**

Several areas for further research have been identified and should perhaps be addressed as a matter of urgency to support people with ataxia and to enhance the effectiveness of physiotherapy.

- a) Further research is required to provide better evidence and advice about maintaining physical fitness and living with ataxia. It might also be useful to identify the most beneficial approaches to exercise, in terms of frequency, intensity and duration, for maintaining function and slowing deterioration.
- b) Further research is required to explore the different life worlds of people with ataxia with appropriate representation of people at different stages of living with ataxia and at different stages of their diagnosis; for example, to explore the development of self-management strategies over time, or the development of new perspectives on disability issues.
- c) Further research is required to investigate the contribution of impaired divided attention to the performance of functional tasks for people with ataxia and whether remedial or compensatory strategies are possible.
- d) Further research is required to investigate fatigue as it is experienced by people with ataxia and to explore the value of early referral to fatigue management programmes.



- e) Further research is required to provide better evidence about the most effective physiotherapy treatments; particularly core stability exercises, strength training, and limb co-ordination training and their impact on everyday occupational functioning.
- f) Further research would be useful to inform physiotherapists and people with ataxia about the most effective home exercise programmes for preserving function and slowing deterioration.
- g) Further research is required to develop the understanding of the role of the cerebellum in motor control. It would be important for this research to have direct clinical utility to inform assessment procedures and to develop targeted treatments for people with ataxia.
- h) Further research is required to investigate service provision and access to services for people with cerebellar ataxia including examination of any centres of excellence, as reported by people with ataxia, to identify best practice.
- i) Further research is required to investigate the underlying assumptions and models that may be used by physiotherapists when treating people with ataxia.

**For more support or information please contact: Ataxia UK, Lincoln House, Kennington Park, 1 – 3 Brixton Road. London SW9 6DE**

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