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

**معاني العلاج الطبيعي للأشخاص الذين يعانون من ترنح مخيخي تدريجي**

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## Abstract

In physiotherapy research, qualitative research techniques that concentrate on the actual lived experiences of patients with health issues are comparatively underutilized. One objective of qualitative health research is to offer a multifaceted understanding of a person's experience with a health condition that goes beyond a basic awareness or common sense awareness and that result in a more knowledgeable, nuanced, and empathic practice. The purpose of this study was to comprehend the significance of physical activity and physiotherapy for individuals dealing with a progressive cerebellar ataxia. This study came to the conclusion that people with ataxia had unique, contextualized understandings of exercise and physiotherapy that might have been very different from what physiotherapists would have in mind. In order to deliver services that are valuable and relevant to people with ataxia, special consideration should be paid to patients' viewpoints. Rehabilitation Implications to provide patients with appropriate exercise prescription and counseling, physiotherapists should think about discussing the meaning of exercise and physiotherapy with each patient. Poorly run and improperly administered home exercise programs run the danger of accidentally ignoring the potential psychological benefits of exercise and may discourage long-term engagement. Exercises that are suggested should be pleasurable, meaningful, gratifying, and sufficiently challenging in order to maintain long-term commitment. Physiotherapists ought to think about offering consistent, team-based, and adaptable services.



**Keywords:** Physiotherapy; ataxia; progressive cerebellar ataxia; exercise; interpretative phenomenological analysis self-selected exercise.

## 1. Introduction

The progressive cerebellar ataxias are a complicated and uncommon category of ataxia-dominant neurodegenerative illnesses that are characterized by dysarthria, dysphagia, and oculomotor dysfunction in the limbs and trunk (Bird, 2015). There are no proven disease-modifying treatments available right now. The cornerstone of the rehabilitation choices available to those who have ataxia is physical therapy; yet, there is a dearth of high-quality evidence supporting physiotherapy interventions for this illness (Revuelta & Wilmot, 2010). Despite the fact that ataxia is a "difficult condition to treat" and that physiotherapists struggle to live up to patients' expectations, people with progressing ataxia may think that physiotherapy is their "last hope" (Daker-White G. G., 2013).

For understanding the perspectives of patients with progressive ataxia or their experiences with physiotherapy, little qualitative research has been done. The significance of exercise for those with ataxia has not been examined in any studies. The most thorough qualitative investigation was conducted by Daker-White et al. (2013) with 38 people who had progressive cerebellar ataxia and lived in the Greater Manchester region of northwest England. They examined their subjective experiences with diagnosis, symptoms, medical management, and physiotherapy services.



These investigations included participation from medical experts, including physiotherapists based in the same area (Cassidy, Naylor, & Reynolds, 2018 ).

People with ataxia indicated a long and difficult journey to diagnosis as well as contacts with professionals who lacked specialized knowledge, which is consistent with findings from an examination of internet discussion boards devoted specifically to ataxia (Daker-White G. S., 2011). Informants emphasized the value of receiving a diagnosis but viewed an idiopathic ataxia diagnosis as unhelpful. According to Daker-White et al. (2013), there was patchy physiotherapy coverage throughout the region, primarily in the form of community rehabilitation provided by the National Health Service (NHS), but there was also funding for private practitioners or no NHS coverage at all. Although they were infrequent, outpatient programs were highly regarded by those who used them.

People with ataxia and certain specialized physiotherapists regularly encountered but criticized the service model of one appointment per week for six weeks followed by a home exercise program. The majority of ataxia participants anticipated "hands-on" care over an extended period of time, but the definitions of this term were not investigated (Bird, 2015). Physiotherapy services should be organized to offer long-term therapy, information, re-referral and support, and techniques of monitoring outcome that were important to patients and healthcare professionals, according to the majority of participants (those with ataxia and physiotherapists). Participants with ataxia who indicated long-term, open-ended, on-going contact with specialized physiotherapists were those who



expressed the greatest satisfaction with the services they received. Daker-White et al.'s (2013) recommendations for an "ideal neurological physiotherapy" service for those with a progressive ataxia were based on these findings.

While Daker-White et al. highlighted the perceived limitations of neurological physiotherapy in the management of progressive ataxia (at least in the UK) and the limitations of service provision from the perspective of people living with this condition, the sense-making that underlie these findings and the meanings participants inferred from their experiences were not thoroughly explored. Data collection and analysis focused on identifying large, overarching themes using the Braun and Clarke method of thematic analysis and were guided by a descriptive grounded theory approach (Braun & Clarke, 2006).

By providing a more in-depth, nuanced, and complex understanding of subjective sense-making, phenomenological approaches to qualitative research can complement other qualitative methodologies and help to further inform clinical practice. Understanding what physiotherapy and "hands-on" therapy might mean to people in the context of living with this condition is important if physiotherapy is thought to be the only option for some ataxia sufferers. It also helps to understand why short-term interventions and home exercise regimens recommended by physiotherapists may not be well received (Finlay, Phenomenology for therapists: researching the lived world. Oxford: Wiley-Blackwell; . [Crossref], [Google Scholar], 2011).



This study used interpretive phenomenological analysis (IPA) to examine and comprehend what physiotherapy, physiotherapy services, and interactions with physiotherapists mean from the perspective of patients with progressive cerebellar ataxia. Additionally, it sought to comprehend the significance of both prescribed and self-initiated exercise, as well as what exercise means in the context of living with ataxia (Smith, 2009). The results of this investigation may aid physiotherapists in better comprehending and attending to the priorities and concerns of ataxia patients who seek their guidance and support (Cassidy, Naylor, & Reynolds, 2018 ).

The IPA methodologies were suitable for examining the meanings of physiotherapy and exercise, which were anticipated to be complex and reflect individual differences in sickness experience, personal settings, and individual interactions with physiotherapists and physiotherapy providers. Researchers who use IPA highlight participant viewpoints above and beyond what may already be thought of as known about the topic and seek for a psychologically close interpretation of a participant's narrative (Smith, 2009). Building sense of and interpreting the participant's viewpoints is a necessary step in the inductive and collaborative process of meaning making and the development of research findings. To investigate and demonstrate the impact of the researcher(s) on the research process and the findings, a reflective analysis is conducted in accordance with the principles of IPA (Finlay, 2008).



## 2. Progressive cerebellar ataxia

Progressive cerebellar ataxia is a rare neurological condition in which there is no effective disease-modifying intervention (Klockgether, 2011). In contrast to multiple sclerosis and stroke, which are both neurological illnesses, little qualitative research has been done to investigate the subjective experience of this complex disorder. One of the rehabilitation options available to those with ataxia is physical therapy, but there is a dearth of high-quality research on which physiotherapists can base their interventions. This study examined the experience of progressive cerebellar ataxia, physiotherapy, and physiotherapy services from the viewpoint of those who live with this condition using interpretive phenomenological analysis (Smith et al., 2009).

Incoordination of the limbs and trunk, dysarthric speech (reduced clarity and intelligibility), dysphagia (swallow dysfunction), and oculomotor dysfunction, such as double vision and vertigo, are all symptoms of ataxia, which means disorder (Marsden and Harris, 2011). Errors in the planning and execution of voluntary action, specifically the direction, amplitude, force, timing, and velocity of movement, are characteristics of ataxic motor behavior (Ghez and Thach, 2000). Ataxia patients have trouble modifying their movement in time and space and acclimating to unfamiliar or challenging surroundings (Morton and Bastian, 2006). Talking, reaching, and walking are just a few examples of how daily tasks are impacted. As a result of their slurred speech and unsteadiness, ataxia sufferers frequently come out as intoxicated (Mulligan, 2012). It is also starting to become clear that non-motor characteristics, particularly



cognitive deficits (such as working memory and visuospatial processing), are a part of the clinical picture. However, more research is needed to uncover the underlying mechanisms and pinpoint the precise deficits (O'Halloran et al. 2012).

Numerous disorders involving the degeneration or loss of cerebellar regions, as well as their links to other sections of the central nervous system, result in ataxia (Ghez and Thach, 2000). Although there is still much to learn about how the cerebellum works, it is well acknowledged that it is essential for the adaptive regulation of motor behavior (Marsden and Harris, 2011).

Simply put, it is believed that the cerebellum compares broad motor commands (rough blueprints for movement) from higher brain centers with internal feedback regarding, for example, the position of the limbs and trunk in space and feedback about external (environmental) variables. The cerebellum recognizes mistakes in the motor plan and inadvertently produces remedial messages by comparing the intended movement with actual world circumstances (internal and external). This fine-tuning modifies movement to conform to the environment (Ghez and Thach, 2000). As a result, the cerebellum handles the fine coordination and execution of action, freeing up higher level control and cognitive effort for other tasks (Smith, 2009).





### **3. Applying the findings of IPA research to therapeutic practice**

A technique to qualitative research known as "interpretive phenomenological analysis" focuses on discovering and comprehending the lived experience of particular phenomena (Smith, 2004). IPA involves a thorough examination of participants' "lifeworlds," or their experiences with a specific phenomenon, how they have made sense of these experiences, and the meanings they have assigned to them. This is because IPA is a methodology in and of itself rather than just a tool for data analysis (Smith, 2004). The benefit of qualitative research for practitioners is that the findings are attuned to issues that could be explored in practice.

Using IPA as a research methodology, one can question accepted discourse or paradigms of thought. The steadfast adherence to idiom may cast doubt on the therapeutic applicability and generalizability of IPA investigations. However, IPA researchers do not discount the significance and applicability of group and population studies, and they are not opposed to establishing broader generalizations; they just do so cautiously and methodically (Smith, Flowers and Larkin, 2009; Smith and Osborn, 2008). rushing into it and enclosing what emerges in current-day systems and frameworks According to Smith, Harré, and Van Langenhove (1995), applying the results of IPA research to therapeutic practice 12 discourses has the danger of misrepresenting the truth of the experience and may result in erroneous assumptions and misunderstandings.



Physiotherapists, for instance, might think about how the new insights affect clinical decision-making. The researchers themselves also have a duty to discuss findings by examining the existing literature and to draw links and highlight discrepancies between the study's findings and the dominant discourse or data (Smith, 2004). As a result, the authors provided crucial advice for physiotherapists on how to assist patients in reinterpreting their perceptions of exercise in the treatment of low back pain.

#### **4. Implications for Working with People with Ataxia**

Cross-disciplinary interest in creating a science of stigma has arisen as a result of the importance of stigma as experienced in a variety of health disorders and the dearth of interventional data (Keusch, Wilentz and Kleinman, 2006). There is no doubt that neurophysiotherapists are involved in this; the feelings of stigma discussed in this study appear to be closely tied to the practice of physiotherapy. Physiotherapists are perhaps well-positioned to consider stigma and help patients recognize and manage their own cognitions about stigma, shame, and the social Implications for Working with People with Ataxia impact of living with a neurological condition by combining a traditional orientation towards the physical body with an understanding of the "body-as-lived" (Whalley Hammell, 2006).

Evidence suggests that protective behaviors may be learnt, and that support and education can help people build resilience and self-confidence (Edward and Warelou, 2005). The limitations of interventions



that rely on the separation of the body, the self, and society into separate spheres are revealed by phenomenological research that reveals the lived experience of illness. Only if practitioners comprehend how these concepts are intertwined in the lives of the people involved will they be able to reduce suffering and contribute to the preservation of health. Physiotherapists are in a unique position to both understand the personal significance of their patients' narratives and their complexity as well as to provide practical support because the pattern of their practice is characterized by intensive, frequently long-term contact with patients (Dean, 2009). An understanding of cognitive behavioral therapy, for instance, might be pertinent to help physiotherapists become more aware of how patients talk about their condition and everyday problems, and it may be a useful intervention to help patients challenge their untested assumptions and consider alternative ways of framing their experience.

Qualitative research that has been rigorously done offers a higher level of evidence than the anecdotal information that underpins much of clinical practice. The idiographic nature of IPA and careful attention to individual stories may reveal intriguing and practical practice-relevant discoveries that contradict commonplace beliefs among physiotherapists. IPA may also serve as a basis for the development of a more contextualized and compassionate understanding of illness-as-lived, enabling physiotherapists to offer services and treatments that are in line with patients' objectives and concerns (Kearney, 2001).

Grounded theory employs bigger samples and is focused on a more macro level of research than IPA. In order to create theories about the



subject of interest, grounded theory focuses on creating codes and categories from qualitative data. In contrast to IPA, grounded theory utilizes theoretical sampling procedures, allowing for the continuing identification and recruitment of participants as a means of testing and refining the emergent categories and theory. Sampling goes on until saturation, which is the moment at which no new data can be obtained through more, sampling. Due to its emphasis on making sense of people's lives and its methodical, step-by-step approach to making more general claims, IPA differs from grounded theory (Mulligan, 2012).

As an emerging method of qualitative research, IPA offers physiotherapy researchers both an opportunity and a problem. IPA should be viewed as a chance to take advantage of a line of inquiry that physiotherapy researchers have not yet fully explored. IPA is well-known in the field of health psychology, and physiotherapists can access a sizable body of work when formulating research questions. But because there is just one critical evaluation of IPA (Brocki and Wearden, 2006), it is difficult for researchers to tell what constitutes "excellent" IPA research from that which is of a lower caliber. The fundamental principles of sound IPA research are established in part by Smith, Flowers, and Larkin (2009), although more systematic review of this topic is warranted. Additionally, in order to engage readers, funders, and editors and to acquire a deeper grasp of IPA and its application to physiotherapy research and practice, physiotherapy researchers may need to carry out additional work. Funding organizations, for instance, might expect physiotherapists who use IPA to be more explicit than is perhaps customary in the IPA



literature about how the findings can be applied to practice in terms of clinical utility and validity.

## **5. Using interpretative phenomenological analysis to inform physiotherapy practice**

One objective of qualitative health research is to offer a multifaceted understanding of a person's experience with a health condition that goes beyond a basic awareness or common sense awareness and that result in a more knowledgeable, nuanced, and empathic practice (Curry, Nembhard and Bradley, 2009). Physiotherapy researchers haven't paid much attention to this kind of qualitative inquiry (Rauscher and Greenfield, 2009). This is the first publication of IPA as a particular kind of phenomenological study in a global journal with a sizable professional readership. Because of its "practical" focus, Dean, Smith, and Payne (2006) suggested IPA for physiotherapy researchers. A number of authors with experience in IPA research have created clear, easily understandable instructions and step-by-step introductions to data collection and analysis. These resources may be very useful for both rookie and more seasoned researchers who are just beginning to use IPA. IPA can be used to study issues of importance to several disciplines, either independently or in conjunction with quantitative methodologies, in the clinical situation and across all specialties.



According to Daker-White et al. (2013), patients with ataxia may see physical therapy as their "sole hope." Additionally, these authors emphasized that patients desired "hands-on" therapy and berated physiotherapists for providing short-term care followed by a home exercise regimen. Physiotherapy represented opportunities for renewal, teamwork, stress relief, and the exchange and accumulation of knowledge. Depending on individual backgrounds and experiences, different aspects of care were discussed and stressed to different degrees. Therefore, it may be appropriate to think of "hands on" treatment as a holistic service delivered by physiotherapists who are actively involved in the design and long-term administration of patients' care rather than in the literal sense.

A substantial body of research supports the idea that physical activity and exercise have positive psychosocial effects and wide-ranging therapeutic benefits for people with a variety of long-term conditions, including restoring self-confidence, minimizing physical impairment and disability, regaining control over physical health and emotional well-being, preserving self-identity, reducing illness-related psychological distress, and fostering senility. Even in cases where it was unclear if exercise had a direct (impairment level) effect, significant psychosocial benefits have been observed (Turner, 2016). Quality of life may benefit from physical pursuits that emphasize amusement and fostering social connections (Motl, 2009).

Similar to this, Mulligan et al. (2012) discovered that engaging in enjoyable but difficult activities gave participants strong sensations of



fulfillment, empowerment, and pleasure that helped them become self-motivating for people with a range of neurological diseases. There are similarities between Scott's involvement in water sports and Graham's involvement in team sports, as well as Julia's self-designed home fitness regimen and Toby's swimming. These were all self-selected activities that presented significant physical obstacles as well as personally meaningful rewards, adding to a sense of accomplishment and satisfaction and providing the drive to continue. On the other hand he described prescribed exercise that was offered in a way that did not suit the preferences of the individual as unfulfilling, unpleasant, and frustrating (Mulligan, 2012).

According to Salmon and Young, patients run the risk of becoming agents managing their own suffering if partnership working is not properly managed and self-management strategies are promoted without being supported by genuinely collaborative practices that take into account patients' vulnerability. Additionally, they discovered that poorly designed home exercise regimens, coupled with insufficient supervision and scant access to skilled physiotherapists, and may increase the burden of managing a progressive ataxia and, as a result, lead to emotions of disappointment, disempowerment, and demotivation (salmon & Young, 2005).

Therefore, rather than just advocating for activities that enhance bodily function or performance, physiotherapists should think about encouraging activities that appeal to intrinsic motives, such as exercising for its own sake of fulfillment and enjoyment. However, our findings also imply that



a number of interrelated psychological variables support persistent exercise participation in individuals with progressive ataxia. These results imply that self-determination theory may offer physiotherapists a wealth of knowledge for understanding exercise motivation. This strategy would possibly call for fresh methods of demonstrating results and might be very difficult for NHS physiotherapists and others who must equally defend and account for services (Teixeira, 2012).

An impairment-focused, home-based approach to exercise prescription may overlook the potential advantages that may be attained from taking a more pluralistic approach to exercise in a situation where there is very little evidence to guide physiotherapy practice and where additional research is urgently needed. Physical activity and physiotherapy can benefit those who have ataxia. However, when the intricate and heavily contextualized meaning of exercise and physiotherapy had not been sufficiently recognized or taken into consideration, participants had poor opinions of physiotherapy and home exercise programs (Keller & Bastian, 2014). These results should motivate physical therapists to thoughtfully and actively investigate the significance of physical activity and physiotherapy with individuals dealing with progressive ataxia. Only by doing this will physiotherapist is able to create satisfying and pleasurable methods for helping people with ataxia maintain physical activity that can simultaneously improve quality of life and help people deal with physical impairment.

To develop long-lasting and sustainable improvements to the care of persons living with long-term conditions, system-wide reforms to the





delivery of health services are required. Physiotherapists still play a critical role in creating patient-centered services that are responsive to patient needs and advocating for better proactive healthcare for many potentially vulnerable members of society who have long-term neurological conditions. However, physiotherapists cannot overcome all of the obstacles to providing sustained, collaborative, and flexible services. Exercise on prescription programs may help people with neurological problems develop their self-efficacy for exercise, but more study is needed to determine the optimal ways to prescribe and deliver this service in order to maximize health as well as psychological and social results (Wiles, 2008).

## **6. Conclusion**

The environment in which physiotherapists work is always changing, posing fresh problems. People who live with HIV/AIDS are beginning to understand it as a long-term rather than a life-limiting condition; pioneering patients and therapists are juggling emerging technical innovations like electrical limb implants, limb transplan, and more. For instance, physiotherapists are working with a growing population of people who are now living into adulthood with conditions that were once considered childhood conditions (e.g., adults living with cystic fibrosis and muscular dystrophy). While for some people, such progress is stubbornly slow, it will continue to change the possibilities for rehabilitation and the experiences of people living with long-term health



conditions. These advances are being made in the therapeutic, pharmacological, surgical, and other medical and nonmedical fields. It is still crucial for research and clinical practice to gain a greater knowledge of what it is like to have these disorders and how clients experience rehabilitation, particularly physiotherapy. People with long-term health conditions may have a better rehabilitation experience thanks to IPA, which provides a way to advance this understanding.

This study has underlined the significance of comprehending physical therapy and exercise from a phenomenological perspective for individuals with increasing ataxia. In this study, the terms "physiotherapy" and "exercise" have distinct meanings that were strongly contextualized. Physical therapy and recommended home exercise regimens were seen to largely focus on the compromised body and, for the most part, did not address the psychological difficulties of living with a progressive ataxia, which were thought to be quite pertinent to the research participants. Self-directed physical activity and activities provided a number of advantages that assisted participants in maintaining their psychological well-being and lowering the prevalence of ataxia in their daily lives. The development of physiotherapy practice and service delivery in ways that would be valued by people living with ataxia could be aided by genuine cooperation between physiotherapists and individuals with ataxia, supported by a contextualized understanding of life with ataxia. These results may prompt physiotherapists treating patients with increasing ataxia to reconsider the purpose of physiotherapy, the value of home exercise regimens, and the manner in which physiotherapy services are



given from the patient's point of view. Additionally, even in the absence of direct effects on impairment level, physiotherapists should think about encouraging and supporting people with ataxia to engage in self-selected exercise regimens and/or sports and activities that are significant to them in the contexts of their own life. It would also be beneficial to conduct more research into how physiotherapists view exercise, home exercise regimens, and their role in treating ataxia patients. A useful way of inquiry may be to employ discursive methodologies to investigate interactions between physiotherapists and ataxia patients.

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