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Enhancing Client-centeredness in Parkinson's Disease Care: Attending to the Psychosocial Implications of Lived Experience

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Abstract

Evidence-based practice requires that clinicians interpret the best research evidence in the context of their clinical experience, while at the same time considering client knowledge and experiences. Although clinicians are becoming increasingly skilled at the evaluation of research evidence, the evidence-based practice process often neglects client values and self-identified health issues. Ignoring these key aspects of client-centered practice may lead to interventions that fail to target the implications of a client's disease that are important to occupational participation and quality of life (QOL). A focus on client-centeredness is particularly important in progressive neurodegenerative disorders, such as Parkinson's disease, where there are no known curative treatments, and interventions must instead focus on symptom management. In this paper, we explore the published literature on the psychosocial aspects of the lived experience among individuals with Parkinson's disease, arguing that such literature provides insight into the implications of the disease and into potential treatment priorities. As such, this literature provides an additional form of evidence that raises awareness of the lived implications of this disease for clients' occupations and QOL that, in turn, may lead clinicians to be more cognizant of client values and self-identified issues.

Keywords

Client-centeredness, Lived Experience, Parkinson's Disease

Credentials Display

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Parkinson's disease (PD) is a progressive neurodegenerative condition characterized by four cardinal motor symptoms, including tremor, rigidity, akinesia/bradykinesia, and postural instability (Jankovic, 2008). Individuals diagnosed with PD may also experience a number of non-motoric symptoms, including pain, sleeping problems, and cognitive changes (Johnson et al., 2004; Johnson, Pollard, Vernon, Tomes, & Jog, 2005). It has also been suggested that neuropsychiatric symptoms, including depression, anxiety, apathy, and psychosis, are common in PD, and affect the majority of individuals at some time during the course of their disease (Aarsland, Marsh, & Schrag, 2009).

Although the physical decline associated with PD has been found to contribute to decreased quality of life (QOL) (Schrag, Jahanshahi, & Quinn, 2000), research has identified that it is actually the non-motoric symptoms of PD that have the greatest impact on QOL for people living with this disease (Hammarlund, Hagell, & Nilsson, 2012). The literature also suggests that neuropsychiatric symptoms can interact with, and exacerbate, both motoric and non-motoric symptoms of PD, thus further impacting an individual's QOL, and his or her ability to engage in meaningful occupations (Giladi & Hausdorff, 2006; Hanna & Cronin-Golomb, 2012; Lieberman, 2006). Furthermore, given that PD is a chronic, progressive condition, individuals experience a decrement in both physical and cognitive capacities over time, which can result in functional limitations and, ultimately, lead to a diminished ability to engage in meaningful

occupations as the disease progresses (Jankovic & Kapadia, 2001).

While PD is most commonly managed pharmacologically by dopaminergic therapy, evidence suggests that individuals with PD may also benefit from various rehabilitative strategies to help maintain their level of functioning as the disease progresses over time. In 2007, Dixon et al. published a Cochrane review that examined the literature on the use of occupational therapy in the treatment of PD. Although this review suggested that clinically meaningful and functional improvements may occur, the varied approaches to treatment and the lack of randomized trials illustrated that additional work needs to be done to develop an evidence base that would serve to assist in establishing practice guidelines.

Given that there are no definitive guidelines for the management of PD, clinicians must base their treatment approach on the best evidence available. Clinicians are becoming increasingly skilled at the evaluation of research evidence, but the evidence-based practice process often neglects client values and self-identified health issues. Ignoring these key aspects of client-centered practice may lead to interventions that fail to target the implications of a client's disease that are important to occupational participation and QOL. Although each person will have a different experience with PD because of his or her unique life circumstances, studies examining the lived experience of PD can serve to heighten awareness and understanding of the ways in which living with a chronic condition influences peoples' occupations, as well as their overall sense of well-being, or QOL.

In this paper, we highlight the literature on the psychosocial aspects of the lived experience of individuals with PD, suggesting that it provides insight into the implications of the disease that merit consideration when working with this population. We believe that this literature will serve to provide an additional form of evidence that raises awareness of the lived implications of this disease for clients' occupations and QOL that, in turn, may enable clinicians to address more fully client values and self-identified issues within their practice. Moreover, we believe this knowledge will help ensure that the therapeutic process remains meaningful to the client, which, in turn, may help to improve adherence and foster a greater sense of empowerment as clients are given the opportunity to become involved with making decisions about their care.

Examining the Lived Experience of PD

We conducted a review of the literature concerned with the lived experience among individuals with PD within PubMed and CINAHL databases using the following key search terms: Parkinson's disease, lived experience, daily life, symptom experience, symptom distress, and illness distress. We selected articles based on their ability to lend support to the notion that lived experience is an important factor that clinicians should consider. Search results revealed that several prominent psychosocial factors are often associated with an individual's lived experience. These factors include unpredictability, preoccupation with time and scheduling, fatigue resulting from cognitive demands, fighting to maintain independence, social

and interpersonal consequences, emotional concerns, and body image insecurities.

Unpredictability

The unpredictable nature of PD symptoms and the medication's side effects is a frequently reported issue within the lived experience literature (Bramley & Eatough, 2005; Haahr, Kirkevold, Hall, & Ostergaard, 2011; Sunvisson & Ekman, 2001). This unpredictability affects an individual's ability to commit to social outings, work responsibilities, and other activities of daily living that support the development and continued enactment of meaningful personal and professional occupation. As the disease progresses, and its unpredictability escalates, individuals begin to report feelings of being imprisoned within their bodies (Bramley & Eatough, 2005; Haahr et al., 2011; Sunvisson, 2006; Sunvisson & Ekman, 2001). Individuals with advanced PD report feeling totally at the mercy of their bodies; these individuals note that they are never able to predict how their bodies will act or react to daily life events, thus taking away much of their personal control (Haahr et al., 2011). For example, Haahr et al. (2011) share the following account of a participant with PD who described the unpredictable on/off fluctuations of the disease as being awkward. "It is awkward.... you cannot plan that in 1 1/2 hour you will be doing this and this, because if the medication doesn't work, whether it is too little or too much, then you are not well. Everything falls apart" (p. 413).

Preoccupation with Time and Scheduling

Individuals with PD, particularly those in advanced stages of the disease, report a perceived need for rigid scheduling of daily activities. As PD

progresses, individuals tend to report an increased level of unpredictability in their symptoms, as well as more severe consequences resulting from not taking medications at their exact scheduled time. In effect, clients report a greater need to abide by a strict schedule when taking their daily medications, and begin to plan occupations according to when they expect that their symptoms will be effectively managed (Benharoch & Wiseman, 2004; Bramley & Eatough, 2005; Haahr et al., 2011). For example, Haahr et al. (2011) recount the following quote provided by a participant with PD who reveals her reluctance to go shopping at certain times of the day. “When we go shopping downtown, locally... I say to my husband, I don’t want to go at noon, because it is medication-time, and it takes some time before it works... I will stand there like a statue unable to move anywhere. People are looking strangely, they really are, and I don’t like it. Even if people in town know that I am slow ... you really don’t feel good... I simply don’t want to advertise for the disease” (p. 412).

Fatigue Resulting from Cognitive Demands

Concerns regarding functional capacity are commonly reported in studies that examine the lived experience of individuals with PD (Bramley & Eatough, 2005; Benharoch & Wiseman, 2004; Haahr et al., 2011). As PD progresses, individuals often develop impairment in their ability to act automatically, exerting high levels of concentration, and using such strategies as “self-talk” in order to conduct basic movements and actions (Farley & Koshland, 2005). These individuals state that basic functions, such as walking, require purposeful effort (Bramley & Eatough, 2005). Basic movements

must also be divided into smaller parts, and calling the body into action requires significant cognitive effort (Sunvisson & Ekman, 2001). Accordingly, both mental and physical fatigue are frequently reported symptoms of the disease, and are important features of the lived experience that may significantly impact one’s engagement in meaningful occupation (Benharoch & Wiseman, 2004; Bramley & Eatough, 2005; Haahr et al., 2011; Sunvisson, 2006; Sunvisson & Ekman, 2001). For example, a fatigued individual is less likely to become active or be inclined to pursue hobbies and interests, and more likely to have a greater tendency to become withdrawn.

Fighting to Maintain Independence

Individuals with PD appear to reject help from caregivers, as part of their efforts at maintaining independence and maintaining an acceptable self and social identity (Roland, Jenkins, & Johnson, 2010). These subtle rejections are often manifested by individuals in their desire to remain engaged in occupations (such as working or driving) for as long as possible after their diagnosis (Benharoch & Wiseman, 2004; Harshaw, 2002). Individuals in more advanced stages of PD may also reject the use of mobility aids, associating these devices with dependency, disability, and weakness (Haahr et al., 2011; Sunvisson, 2006). Thus, although the use of a mobility aid is an important marker of neurological progression in PD, often indicating that an individual’s balance has been affected, not everyone with PD experiencing balance impairment will be accepting of this technology. Consequently, these individuals may be hesitant to engage in occupations resulting from

a heightened fear of falling.

Social and Interpersonal Consequences

Individuals with PD report social withdrawal and impaired social abilities. This results from feelings of embarrassment or apprehension about experiencing physical symptoms (e.g., tremor, falling, shuffling gait, intermittent bouts of sweating) in public (Bramley & Eatough, 2005; Haahr et al., 2011; Sunvisson, 2006; Sunvisson & Ekman, 2001). The experience of facial masking appears to have an especially great effect on social involvement and one's level of comfort when interacting with others. This discomfort develops from the conscious awareness that others may misinterpret a masked facial expression (Haahr et al., 2011; Harshaw, 2002). For example, as one participant states in Haahr et al. (2011), "When I go OFF Then my face 'dies'. My mimic is gone and I am kind of gone too. . . . I am not that sociable when I am OFF" (p. 412). As the disease advances, social withdrawal, including decreased participation in occupations with others, appears to worsen, with individuals reporting heightened levels of apprehension as symptoms become more unpredictable in nature (Haahr et al., 2011; Sunvisson & Ekman, 2001). Interestingly, individuals have indicated that it is not concern over public symptoms that causes the greatest distress, but rather the presentation of symptoms in front of close friends and family. Sunvisson and Ekman (2001) reported that individuals with PD felt more severe embarrassment in front of those closest to them, explaining that they did not wish for these important individuals in their lives to see their limitations or weaknesses. Sunvisson and Ekman

(2001) also suggested that social withdrawal appears to result as a consequence of the cognitive and motoric slowing associated with PD. For example, individuals may withdraw or limit engagement in social activities if they perceive it is impossible to make timely or appropriate conversational responses, or to finish a meal within a socially acceptable amount of time.

Emotional Concerns

Some commonly reported emotional concerns among individuals with PD include feelings of frustration, anger, and depressed mood. The source of much of the frustration and anger comes from decreased levels of mobility and a perceived lack of control over functional motor actions (Benharoch & Wiseman, 2004). In a personal account, Tichler (2010) described frustration as resulting from feelings of being undeserving of a disabled life. Other individuals report feeling an almost overwhelming sadness associated with their experience of the disease. For example, Harshaw (2002) described PD as a persistent struggle with depression, a finding that is not all that surprising given the high rate of comorbidity among depression and PD (Aarsland et al., 2009).

Managing Tensions Between Bodily Appearance and Sense of Self

Individuals with PD are not only affected by the functional capacity of their body, but also by changes in physical appearance. Both men and women with PD report experiencing distress as a result of their changing physical appearance. For example, Haahr et al. (2011) report that individuals with advanced PD often feel as though their bodies

are “alien” to them, and note that this negatively affects their self-esteem and perception of personal identity. Harshaw (2002), in his personal account of living with PD, described himself as being “grotesque” and “freak-like,” and said that he assumed that people no longer wished to be around him due to his appearance. Dominant within much of the current literature on the lived experience of PD is the desire of individuals to be able to present themselves as who they “actually are,” as opposed to their perception of being seen in a state that has arisen as a result of their disease (Bramley & Eatough, 2005; Haahr et al., 2011; Harshaw, 2002).

Clinical Implications

This summative, descriptive review of key thematic elements within the literature addressing the lived experience of PD brings to light a number of potential barriers to the development of meaningful occupations among individuals with PD. At issue, of course, is how this information may be incorporated into clinical practice.

One manner in which this can be realized is for occupational therapists to ask their clients probing questions informed by the lived experience literature. For example, occupational therapists may be able to implement a more client-specific approach to fatigue management by using their knowledge of the lived experience of PD to inform their questions and strategies. The typical process for fatigue management involves reviewing a person’s daily routine, prioritizing tasks, restructuring activities according to energy levels, introducing regular rest periods, and teaching good sleep hygiene (Jahanshahi & Marsden, 1998). Such guidelines are, however, focused on the physical

aspects of fatigue, which may not be of the utmost importance or relevance to an individual client. Relating such suggestions to the literature reviewed in the present paper, occupational therapists may benefit from asking their clients questions that reflect cognitive fatigue, such as whether they need to “self-talk” and, if so, how clients perceive the impact on their cognitive functioning.

A second domain of clinical practice that is facilitated by investigating the lived experience relates to research suggesting that individuals with PD engage in poor help-seeking behaviors (Roland et al., 2010), meaning that they tend not to ask for assistance when needed. Individuals who refrain from asking for help risk exacerbating their social isolation and potentially reducing their ability to learn of (and implement) better social, cognitive, and motoric strategies (particularly with regards to the use of support services and assistive devices). Client education and referral for support services may have the effect of encouraging individuals with PD to accept the help they need. Although this may appear to be in conflict with an occupational therapist’s goal of increasing and maintaining independence, positive help-seeking behaviors may actually serve to increase autonomy and strengthen the capacity to engage in those occupations most meaningful to an individual. For example, by receiving help with particularly fatiguing tasks (e.g., getting dressed), the individual with PD may retain energy to engage in additional activities that may hold more significant meaning (e.g., gardening). Improving the help-seeking behaviors of an individual with PD can, however, be particularly challenging when the primary caregiver is a family

member or close friend. As previously discussed, Sunvisson and Ekman (2001) suggest that individuals with PD feel more severe embarrassment in front of those closest to them, and do not wish for these important individuals in their lives to see their limitations or weaknesses. Thus, although in typical practice occupational therapists may make the recommendation that individuals with PD accept help from those close to them, the aforementioned literature on lived experience suggests that, in fact, it may be more appropriate to arrange an outside agency to provide assistance. Doing so will help the client retain dignity within the relationship, and will preserve the roles of the client and family member or friend outside the caregiving relationship.

More important, not only can evaluation of the lived experience benefit clients, it may be an asset to reducing caregiver distress. As discussed in Roland et al. (2010), caregivers often view social outlets as a means of distraction, rather than as a source of support. It is, therefore, important for health care professionals to consult caregivers to ensure that they are not in distress, as this may lead to a further deterioration in social relations, both at home and in the community. This can be a challenging conversation for the occupational therapist, as the role of caregiver is likely entangled with the role of family member. This may be particularly problematic in the case of spousal caregivers. The family member may feel an obligation to provide care without relying on outside agencies, even to the point where outside assistance is seen as a betrayal of his or her relationship with the client.

The foregoing suggests, therefore, that it is important for clinicians to identify the needs and wishes of both the client and the family caregiver. It is entirely possible that the client does not want to receive care from the family caregiver, and that the family caregiver would prefer to engage the services of an outside agency. It is also possible that neither will be willing to verbalize his or her preferences. The occupational therapist must take care to ascertain the true wishes of the client and the caregiver, and work to balance the importance of caregiving needs and family roles.

In this paper, we have discussed the benefits of incorporating research on the lived experience of PD into the evidence-based practice process. A client's lived experience informs his or her values, occupational goals, and expectations for treatment, and this is a critical consideration for the clinician in the implementation of the best possible interventions. As PD remains a chronic and progressive disorder, with highly variable impairment of motor and non-motor function, it is crucial that treatment interventions be individualized, client-centered, and focused on improving day-to-day QOL via enabling occupational participation. The consequence of this focus on client values may lead clinicians to treat PD more holistically and reduce the focus on physical symptoms that may or may not be of primary concern to the client. As presented in this paper, this refocusing on the psychosocial outcomes of PD is entirely in keeping with the current research on patient values in this population.

Moving forward, in order for occupational therapists to fully integrate knowledge on client

values and perspectives of living with PD into practice, thereby enhancing client-centered evidence-based practice, there is a need to identify clear linkages between increasing clinician awareness of the lived experience and positive outcomes, such as increased occupational engagement. In doing so, clinicians may increase

their knowledge of the spectrum of challenges experienced by their clients, thus allowing them to become more attuned to the specific needs of these clients in their day-to-day lives.

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