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Exploring quality participation through dance movement therapy for Parkinson's Disease

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Abstract: The purpose of this study was to explore the utility of the six quality participation (QP) elements developed for physical activity programs for individuals with disability (autonomy, belongingness, challenge, engagement, mastery and meaning) within the context of dance movement therapy for individuals with Parkinson's Disease. This is a single-case study with semi-structured interviews that involved eight participants (six women and two men) from a dance movement therapy program for individuals with Parkinson's Disease, to explore participants' experiences within the context of the QP elements. Data were analyzed using reflexive thematic analysis. Autonomy, engagement, and belongingness were identified as contributors to QP experiences. Insights were gained on the relevancy of the QP elements to assess QP among individuals with Parkinson's Disease in a dance movement therapy physical activity program. Findings also highlight potential nuances in the understanding and application of the QP elements for different populations with disabilities. In this case study, three of the QP elements had utility *in situ* and advanced our understanding of the multidimensional nature of QP for individuals with Parkinson's Disease.

Keywords: adapted physical activity, disability, autonomy, engagement, belongingness

Introduction

Parkinson's Disease (PD) is a neurodegenerative disease, predominantly affecting those over the age of 65, with an estimated 10 million people worldwide diagnosed with the disease (Parkinson's Foundation, 2022). Individuals with PD experience a decrease in dopamine, a chemical integral for the brain's motor control system. Symptoms include tremors, improper balance, slurred speech, rigidity, and stiffness of muscles (Parkinson's Foundation, 2022). Additionally, some individuals with PD develop depression or anxiety as a result of psychosocial factors such as the loss of a valued self-identity, the perception of being a burden on others, or a sense of disengagement from their community (Charmaz, 1983; Kelly & Field, 1996). Physical activity is highly recommended for those with PD as it can improve mobility, flexibility, balance, muscular strength, short-step gait, posture, perceived functional independence, progression of PD symptoms, and quality of life among individuals with PD (Baatile et al., 2000; Crizzle & Newhouse, 2006; Goodwin et al., 2008; Parkinson's Foundation, 2022). Physical activity has also been shown to improve mental health for individuals with PD, including improved motivation, positive mood, depression, and anxiety (Ahlskog, 2011). Although physical activity can mitigate symptoms of PD (Baatile et al., 2000; Crizzle & Newhouse, 2006; Goodwin et al., 2008; Parkinson's Foundation, 2022), physical activity participation is low in this population and individuals with PD are at high risk of physical inactivity due to these same symptoms (Cavanaugh et al., 2015).

Given the positive effects of physical activity for individuals with PD, there is value in examining how physical activity interventions can be optimized to support participation and adherence. Recent research on individuals with disabilities has highlighted an often overlooked component of participation – quality – as essential to beginning and sustaining participation (Martin Ginis et al., 2017). Six experiential elements of participation have been associated with quality participation (QP): autonomy (i.e., a sense of choice or control); belongingness (i.e., a sense of connection and acceptance); challenge (i.e., feel appropriately tested physically and psychologically); engagement (i.e., feel focused and immersed); mastery (i.e., accomplish new things or improve skills); and meaning (i.e., participation supports personal or social goals). These six elements should be considered when conceptualizing and operationalizing participation within a physical activity program of interest (Evans et al., 2018; Martin Ginis et al., 2017). Research on the QP elements has further identified programmatic conditions (the physical environment, the program, and the social environment) that are essential foundational components for the QP elements to be experienced (Evans et al., 2018). To our knowledge, no research has examined QP within a physical activity setting among individuals with PD. This is a critical knowledge gap as physical activity for individuals with PD may be a unique context compared to the parasport contexts that had characterized existing QP research, and individuals with PD are a special population given the characteristics of their condition. Accordingly, the current study aims to extend the existing conceptualization by exploring QP for people with PD within a dance movement therapy (DMT) program.

DMT is a practice that simultaneously engages somatic, emotional, and perceptual processes, focusing on using physical activity to manage both motor and non-motor PD symptoms (Hanna, 2007). DMT has been found to improve physiological symptoms, including posture, balance, gait, range of motion and tremors among people with PD (Bearss et al., 2017; Hackney & Bennett, 2014; Houston & McGill, 2013; Westheimer et al., 2015). DMT also increases perceptions of quality of life among people with PD (Hackney & Earhart, 2009; Heiberger et al., 2011; Westheimer, 2008). To date, much of the research on the experiences of people with PD participating in DMT programs have used quantitative assessments of physiological aspects and symptoms of PD or quality of life (Hackney & Bennett, 2014). There has been a dearth of research exploring DMT from a qualitative perspective, with little concentrated attention paid to the *quality* of physical activity experience for DMT participants. By taking a qualitative perspective, key experiential aspects of QP for individuals with PD can be better understood. This paper takes a case study approach to explore the utility of the QP model for understanding the experiences of individuals with PD participating in a DMT program called Dancing with Parkinson's.

Materials and Methods

We present findings from a single-case study conducted with a specific focus on the utility, strengths, and limitations of the QP elements *in situ*. This approach is an opportunity to carry out for in-depth and rich exploration into participant experiences. Furthermore, one author (EE) was a volunteer dance coach for the Dancing with Parkinson's program, which provided opportunity for greater reflexivity and a baseline of trust and understanding with the program and potential participants.

The research team recognized the lack of research when it came to the application of the QP elements to real-life physical activity programs and, in particular, DMT for persons with a disability. The Dancing with Parkinson's program aims "to enhance the mental and physical health, and social well-being of adults affected by PD through a specially-created dance therapy and movement program designed to enhance and improve participants' physical activities" (Dancing With Parkinson's, 2018). Dancing with Parkinson's is a

charitable organization that seeks to reduce isolation among people with PD by providing opportunities to connect with others through dance. Program staff seeks to provide a safe, accessible, and inclusive program environment focused on movement and the arts. Classes are specifically designed for people with PD of every dance level and physical ability. Different class and music options are provided to accommodate different interests and desired program frequency and engagement. The program provided an ideal opportunity to improve knowledge of the quality of experiences of individuals with PD in DMT programs and physical activity programs more broadly.

Philosophical assumptions

The research team represented individuals with both programmatic and academic experience with physical activity across diverse populations of individuals with disabilities, including PD. Members of the authorship team had also been involved in the development of the Quality Parasport Participation Framework (Evans et al., 2018) which situates the six Quality Elements of Participation within evidence-based best practice guidelines for optimizing the delivery of quality physical activity participation for individuals with disabilities (Canadian Disability Participation Project, 2018). Based on our previous experience with qualitative research exploring physical activity programs for people with disabilities, we understood that the experience of disability is multifaceted and multidimensional, influenced by a number of factors including characteristics of the impairment, demographic characteristics, an individual's response to their impairment, their interaction with society, and the larger sociocultural perceptions of disability which frame an individual's social engagement and opportunities. As such, this study was grounded ontologically in relativism and epistemologically in constructivism (Sparkes & Smith, 2013). This study was thus conducted with the intent of understanding patterns in participant perspectives reflective of QP while grounding our knowledge and interpretations within the context of participants' individual experiences and reality.

Participants

Following approval from York University's institutional research ethics review board (STU 2017-155) and the director of the Dancing with Parkinson's program, study participants were recruited during classes (convenience sample) and through snowball sampling (Marshall, 1996). There were no exclusion criteria regarding the age, sex, or the severity of disease. The Director of the program assisted with participant recruitment by disseminating information about the study to members via email. Study participants who enrolled in the Dancing with Parkinson's program were seniors with self-reported severity of PD symptoms ranged from mild to severe. Given that this was a case study, focused on one specific program, in a specific location, during a delineated period of time, great care was taken to ensure the confidentiality and anonymity of participants. Pseudonyms were used to protect the participants' identities and individual demographic information was not collected.

Data collection

Each participant attended a single in-person one-on-one semi-structured interview (20-60 minutes in duration) conducted by the second author (EE). There was a foundation of trust upon entry into the interview given the interviewer's previous experience volunteering with the DMT program and participants. The interviews were audio recorded, and notes were taken during and after the interview. Interviews were transcribed verbatim by the interviewer.

The interviews operated as guided conversations with open-ended questions, providing participants with opportunities to direct dialogue (Hermanowicz, 2002; Warren & Williams, 2008). This format allowed the interviewer to address specific dimensions of the research, while also allowing participants to lead understanding of what was important to their participation, offer unanticipated insights, and inform new directions for follow-up questions or prompts as part of an in-depth account of their experiences (Galletta, 2012). The interview started with two opening questions to help the participants feel comfortable with the interview format (e.g., How did you first become involved with the Dancing with Parkinson's program?). The interviewer then transitioned to six questions, each of which linked back to one of the six QP elements (e.g., How do these dance classes make you feel?). Follow-up probes dove deeper into the concepts while also providing a jumping-off point for deeper discussions on participation (e.g., Describe the relationship you have with your instructors.). Questions posed were altered in form or order at the time of the interview based on the responses of the participants. This format facilitated more natural conversations between the researcher and participant while also keeping both centered on the study purpose (Hermanowicz, 2002). The interview ended with closing questions providing the opportunity for the participant to share additional thoughts or comments and ask the interviewer questions (e.g., Is there anything that we didn't discuss that you feel is important to this discussion?).

Data analysis

Data were analyzed using reflexive thematic analysis (Fereday & Muir-Cochrane, 2006). Analysis was led by the researcher who had conducted the interviews and had previous experience with the program. However, the other authors were engaged throughout the process, meeting with the researcher regularly for in-depth discussion on the meaning of the data, the researcher's own experiences and knowledge with the program, and the concept of quality participation. First, transcripts were read and re-read for the author to immerse themselves in the data. During this phase, the author took notes on their thoughts from the interviews, including anything surprising, such as certain responses brought to mind their own program experiences or any other research from the literature. During this phase, transcripts were also distributed to the other authors for review and in-depth reading so the whole team could engage in informed discussions based within the transcripts. After this process and a group discussion about the transcripts with other authors, initial codes were created inductively by identifying individual meaning units representative of each participant's experiences. These codes were then organized into themes and sub-themes. These themes were then further developed and refined through additional discussion with the co-authors and an iterative review of the data set (Braun et al., 2018). The themes were then examined deductively in relation to the six QP elements. This process included extensive discussion among the research team, which included individuals involved in the development of the QP framework. Throughout all steps, the study team engaged in continuous review of the transcripts and interviewer notes. The authors also engaged in the process of 'mutual collaboration', by ensuring that group discussion included consideration of everyone's diverse perspectives and background, as well as the perspectives of the participants and the latent meaning within their statements.

Research quality

The quality of this research was guided by 20 questions for assessing research quality in thematic analysis (Braun & Clarke, 2020). The questions may be used throughout the research process and focus on two domains: adequate choice and explanation of methods and methodology, and a well-developed and justified analysis. An additional prominent

quality practice was sincerity. The author (initials) who led the interviews and analysis engaged in self-reflexivity through the use of a research journal (Guillemin & Gillam, 2004). This process was essential to allow the author to take a critical look at their role in the research process and interpretations of the data, particularly given their prior experience with the DMT program. A complimentary practice to explore whether and how prior experience or interactions may have influenced data collection or interpretation was regular meetings with other team members. These meetings included intense critical discussion among the research team during which members of the team acted as 'critical friends' for the researcher leading the analysis. As critical friends, the research team focused on encouraging the researcher to dig deeper into alternate understandings and interpretations of the data. Through the research team's diverse backgrounds and experiences, this allowed the team the opportunity to explore varied meanings in the data.

Results

All participants identified this DMT program as a valued way in which to remain active. Ramona answered that her reason for participating in Dancing with Parkinson's was: "It's either a choice of getting out of the house and coming to class or staying in bed with the covers over my head, which is not really a choice." She further added that her choice to come to dance was driven by "the desire to keep on living." Our analysis identified three QP elements as contributing significantly to QP experiences: autonomy, engagement, and belongingness.

Autonomy: Supporting participants to move in the way they want

Autonomy is defined as experiencing independence, choice, and a sense of control during physical activity participation (Martin Ginis et al., 2017). Participants identified this QP element as a vital feature of their DMT experience. However, the participants did not experience autonomy as complete freedom or functional independence per se. Rather, autonomy was understood as an ability to make meaningful choices about their own bodies and bodily practices in class. PD critically reduced the participants' independence, but the Dancing with Parkinson's classes offered them opportunities to choose how to move their bodies as the instructors served as guides or facilitators of the dance movements. Instructors maintained a focus on participant safety while fostering the idea of "do what you can," which made the class "relaxing" and "fun" according to participants. Pip expressed, "My whole being feels happy because I am able to exercise." The participants were motivated to attend the DMT program to be physically active. Having an opportunity for autonomy through their execution of movement, while also feeling secure in their safety, appeared to contribute to a sense of QP.

Participants valued the freedom to decide for themselves on how and to what degree they would perform each exercise and how they would perform them. Stevie described the program as "safe and positive." The participants felt as though they were not pressured to ever perform beyond their individual comfort. The value placed on the ability to make choice without pressure from others demonstrated how the feeling of autonomy was meaningful for the participants in this study.

Engagement: Experiencing flow through challenges and mastery

Another QP element highlighted by the study participants was that of engagement. Engagement is defined as the feeling of being focused, motivated, and experiencing flow (Martin Ginis et al., 2017). In this study, participants described their experiences during the classes as fun and positive, while simultaneously expressing the fact that their full concentration was solely on the dancing. One participant, Stevie, described feeling a sense

of flow. Flow is defined as a complete absorption in and engagement with what one does (Nakamura & Cskizentmihalyi, 2014). This flow experience was also described by other study participants. The participants expressed that the challenges provided for them by the dancing stimulated their desire to focus. They also underscored how the feeling of accomplishing the activities further motivated them to focus and engage in the DMT.

In the QP framework (Evans et al., 2018; Martin Ginis et al., 2017), the elements of challenge, mastery and engagement were presented as separate elements that make up a quality experience. However, in this case study, the participants seem to describe the elements as interacting with one another, with engagement being the experience produced by challenge and mastery. This is not a new concept for the QP framework, or indeed in psychology research, as it has been suggested that flow is the result of appropriate challenge consistent with one's capacities, combined with clear proximal goals and immediate feedback when progress was made (Csikszentmihalyi, 2000). For the DMT participants, the exercises were appropriately challenging. Bridget described the exercises as "a challenge that's doable. It helps your body feel organized and to improve coordination." The participants often described the exercises as having a complexity that required focus and coordination between the body and mind. This challenge was motivating for the participants.

Feelings of mastery coincided with challenge through improvements in the participants' dance technique or in their physiological symptoms. Bridget shared some of the goals she had for herself: "I want to get everything right and improve my coordination." She later explained how good it felt when she did get the dance steps right or "manage" to learn the dance moves in class. Bridget illustrated how the goals and improvements were motivating and led to further engagement in the class. Other participants similarly demonstrated how their motivation for being attentive in class came from these accomplishments and improvements, even those felt by their fellow participants. Wanting to continue to achieve mastery and tackle challenges, the participants became more attentive during class and less distracted from problems outside of the class, even for a short time. This finding reinforced how a sense of engagement was key in a quality physical activity experience for the participants, and that engagement was interwoven with a sense of being challenged and feeling mastery.

Belongingness: Valued relationships with instructors

The third QP element identified was a sense of belongingness. Martin Ginis and colleagues (2017) identified belongingness as an experience leading to QP and defined it as the building of relationships that makes one feel accepted and respected on an interpersonal or social level. Participants explained that their relationships with the instructors were most significant in making their experiences satisfying and enjoyable. As Stevie described,

> And I would say the instructors make it worthwhile because when I ended Dancing with Parkinson's, and then the program was over, I had to find something else. And somebody was coming in to teach yoga, well that's when I said "I'll stay for that" but I didn't feel that she had any interest in what she was doing, or in us, and it was a funny feeling, because I decided I'm not going to come back to this. So, it's obvious, but it's really important that the [Dancing with Parkinson's instructor] has her class in mind and that that's kind of conveyed in how she acts.

Here, Stevie noted that she preferred the Dancing with Parkinson's instructor because she felt the instructor cared about helping those who attended the classes, which motivated her to further engage in the DMT program and prompted her to not continue with yoga.

Very few participants found their relationships with class peers or other volunteers to be of significance to facilitate a sense of belongingness that contributed to a QP experience. For example, Bridget explained, "Well, if people want to socialize, we should organize ourselves to have coffee after class or something. I talk to people on the elevator and going up and down, during the classroom water break is enough socializing for me." That said, despite an apparent lack of importance placed on developing relationships with peers, participants did perceive value in participating alongside people with similar physical conditions. To the question of whether the presence of other participants motivated his attendance at class, George answered: "No, I come to class whether the friendships or not." Despite the participant acknowledging the "bonus" of socializing while at Dancing with Parkinson's, relationships with other participants were claimed to not be a factor influencing participation. Conversely, for several participants, the connections they developed with the instructors were a central reason for them returning to the class. Thus, for this study, the QP element of belongingness did not just relate to relationships with peers but relationships with their DMT instructors.

Discussion

This paper explored the experiences of people with PD participating in DMT with a specific focus on better understanding participants' experiences through the lens of the QP elements (Evans et al., 2018; Martin Ginis et al., 2017). Analyzing these experiences can improve understanding of the utility of the QP elements for research on quality physical activity participation for people with PD. As described above, the study determined that three of the six QP elements; autonomy, engagement and belongingness, were significantly related to the quality of the physical activity for people with PD in a DMT program. The elements of challenge and mastery were found to relate to engagement while, interestingly, the QP element of meaning was not identified in the data. Meaning is defined as feeling that through one's participation an individual has contributed to personal or socially meaningful goals (Martin Ginis et al., 2017). Even though personal goals were mentioned by study participants, the analysis highlighted that this conceptualization of meaning did not play a significant role in participants' sense of QP and those goals were linked more to mastery of skills than a sense of growth or contribution. To be clear, participants found the DMT program meaningful, but not in a way that fits neatly within the QP elements. The strong thematic presence of autonomy, engagement, and belongingness suggested that these QP elements had a high value in providing a framework for informing improved QP for people with PD, with some limitations that warrant further discussion and, ultimately, more applied research.

Adding nuance to notions of autonomy, engagement, and belongingness

In this case study, the QP elements of autonomy, engagement and belongingness resonated strongly with the study participants. For people living with a disability, physical activity experiences that foster feelings of autonomy can increase intrinsic motivation and perceived independence (Banack et al., 2011; Boyle, 2008). Participants emphasized that having support to make choices about their bodies and movements in class, without pressure from the instructors, was vital in their enjoyment and in their perception of DMT as a quality physical activity experience. This finding aligns with the definition of autonomy as provided by Martin Ginis and colleagues (2017). Yet, the data from this case study also highlighted how the definition of autonomy may benefit from greater nuance to include mixed or co-created autonomy. In this case study, the participants made it clear that the DMT instructors gave them options and guided them through the dance, but because of the participants' PD-related motor-control issues, their full independence in the DMT classes was not possible.

The Dancing with Parkinson's classes were structured to a large degree and the instructors were actively involved in guiding and facilitating movement options for, *and* with the participants. The results supported a definition of autonomy where there was an emphasis on a mixed or co-created autonomy whereby autonomy was encouraged through an active exchange of ideas and the sharing of power between the participants and the instructor (Quill & Brody, 1996).

The need to consider more nuanced definitions of the elements was also identified with the concept of engagement. A major finding of this study was the value placed on being engaged during class, with participants enjoying the fact that their attention was solely on the dancing to the point where it seems as though time disappeared. Also noteworthy was that the concept of engagement was interwoven with two other elements: challenge and mastery. The challenge of the dance activities led to the participants' perceived need and desire to immerse themselves (i.e., engage) in the activities during class. The sense of mastering the dance moves provided participants with a sense of accomplishment and motivation to continue. In this study, the three QP elements were interconnected whereas Martin Ginis and her colleagues (2017) present them as somewhat distinct. Future research on the nuanced relationships between engagement, challenge and mastery would be meaningful as it may help physical activity program developers better attend to and foster the features of their programs to encourage QP experiences for people with a disability.

Reeve (2006)0000-00-00 0:00:00 AM framed disability as a form of social oppression involving not only restrictions on activities because of impairment, but also because of inaccessible and unaccommodating social structures that served to reproduce ableism and, in turn, marginalize those with disabilities. Being excluded from participating in physical activities defined those with disabilities as different and not belonging to mainstream society (Reeve, 2006). The Dancing with Parkinson's program provided participants with an opportunity to be and feel included as physically active people despite living with a disease that, over time, took away their control of their bodies. In this sense, the QP element of belongingness – the feeling of being accepted into a group or society – was relevant and significant. However, from this case study, we highlighted that, for these participants, while being with others who had PD was important, it was a sense of connection to the instructor that was most critical to their perceptions of belongingness and QP. This stood in contrast with other studies of physical activity programs for those with a disability where a greater weight was placed on feelings of acceptance and respect gained through meeting people who share the same disability (Shirazipour et al., 2017). One potential reason for the unique finding in the present study could be that although Dancing with Parkinson's was a group class, group-based activities were not emphasized, the class provided limited opportunities for the class members to interact with one another. Researchers may benefit from exploring more nuanced understandings of the QP elements including belongingness. Clarifying that not all relationships in a program were sources of belongingness and there should be flexibility in how QP elements should be applied in physical activity programming.

Limitations

A potential limitation was selection bias. All participants were effusive in their praise of the program. Given that participation was voluntary, it is likely that those who were enjoying the program more and seeking to support the program were most interested in participating in research interviews. Furthermore, while the interviewer's previous experience with the program was a benefit in providing the research team for the opportunity for greater knowledge and depth of engagement with the program, as well as a more comfortable and trusting interview environment, their identifiable role as a volunteer with the program may have made participants less likely to share constructive or negative feedback on the program.

It must be noted that given the case study approach employed, the results of this study may not necessarily be generalizable to all DMT programs or to all physical activity programs for individuals living with PD. As such, rather than suggesting that the QP elements should be adapted for people with PD, findings should be interpreted as providing improved understanding of the QP elements within the context of DMT and experiences. Further research should consider including participants who represent a larger group and consider gaining insight from DMT program developers or volunteers.

Conclusions

The objective of this paper was to explore the experiences of people with PD participating in a specialized DMT program with a specific focus on exploring the utility, strengths, and limitations of the QP elements as developed by Martin Ginis and colleagues (Martin Ginis et al., 2017). A strength of the QP elements was that they provided a clear framework with which to explore the experiences and perceptions of those with a disability in physical activity and, in turn, helped researchers and program developers create QP physical activity opportunities for people with a disability. The six elements enabled a systematic approach to exploring what was a complex and multidimensional phenomenon but also created challenges in the analysis of the data as there was a tendency for overlap or lack of clarity among the elements. Nevertheless, the breadth of the elements encouraged broader consideration of what meanings, satisfactions, and experiences the participants shared, and how the QP elements could continue to be strengthened. In this case study, three of the QP elements had utility *in situ*, and advanced our understanding of the multidimensional nature of QP for people with PD. We strongly encourage the continued application of the QP elements in physical activity programming for people with PD, as well as continued research on the application and versatility of the QP elements. The use of the QP elements also allowed us to better understand the strengths and limitations of the elements themselves, directing us to consider how more clear, nuanced, and interconnected definitions would enrich the concept of QP. This case study offered us a glimpse into what participants with PD found satisfying from a DMT program. Expanding our understanding of the experiences of people with disabilities, in addition to increasing the depth and breadth of our knowledge of the QP elements is valuable to inform optimal physical activity experiences for people with disabilities. Furthermore, as we gain greater understanding of the value of these programs and how to create QP within programming, researchers should further consider how QP within a DMT program may contribute to a larger sense of inclusion within society.

Perspectives

The findings presented in this paper have important implications for the field of adapted physical activity, particularly for individuals with PD. The recommendation of physical activity, such as DMT, as a means of improving of improving PD symptoms and quality of life highlights the potential of non-pharmacological interventions for managing PD. Moreover, the identification of autonomy, engagement, and belongingness as key contributors to quality experiences in DMT programs underscores the importance of person-centered approaches in designing and implementing physical activity programs for individuals with disabilities. The emphasis on challenges and mastery experiences as related to feeling engaged during DMT participation also highlights the potential of tailoring physical activity interventions to individual needs and preferences. Finally, the use of the Quality Participation Framework as a tool for optimizing physical activity experiences for people with disabilities provides a practical and evidence-based guide for practitioners in the field of adapted physical activity. Overall, this manuscript represents a valuable

contribution to the practice of adapted physical activity and has the potential to inform and improve the design and implementation of physical activity programs for individuals with PD and other disabilities.

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