

**EXPLORING DANCE MOVEMENT THERAPY AS QUALITY PHYSICAL ACTIVITY
FOR PEOPLE WITH PARKINSON'S DISEASE**

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Abstract

This project explores the quality of physical activity people with Parkinson's Disease (PD) experience via a case study of a specialized Dance Movement Therapy (DMT) program, Dancing with Parkinson's (DwP), based in Toronto, Ontario, Canada. Organized around six major themes (autonomy, belongingness, challenge, engagement, mastery and meaning), the Quality Participation (QP) model developed by Martin Ginis and colleagues (2016) served as the framework by which participants' quality participation experiences in the DwP program, including the meanings and satisfactions they derived from participating in the program, were investigated. The objectives of this study were twofold: to explore the quality experiences of PD patients participating in the DwP program, and to better understand participants' experiences in DMT through the lens of the QP model. Drawing on qualitative research methods, semi-structured interviews were conducted with eight participants (two male and six female) from the DwP program. Thematic analysis of the data highlighted three key conditions that enabled the participation in the DwP program (physical environment, activity and social environment), and foregrounded three of the six themes defined in the QP model (autonomy, engagement and belongingness). This project aimed to contribute to research on DMT and to quality physical activity participation in general, with focused attention on participation among populations with PD specifically

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Chapter 1: Introduction

Dance has always played a crucial role in my life. I use dance to get through life's difficult moments, to express myself, my joys, my sorrows, my passions and ideas. I could not imagine my life without dance. Coming to understand how much dance means to me led me to become curious about what role dance plays in other peoples' lives. In particular, an interest in looking at dance from a therapeutic perspective began burning inside me. This interest finally ignited into action after just one day of volunteering at the Dancing with Parkinson's (DwP) program.

Prior to the class I found myself worrying for the participants, asking myself: how will these people suffering from a disease that causes problems with movement ever be able to enjoy a class where everything is about movement? But what I discovered amazed me. The atmosphere of the class was uplifting and joyful. The movement of the participants appeared to be uninterrupted for an entire hour. From the looks of it, everyone was enjoying themselves. One woman in particular got my attention. I noticed her hands would constantly shake as she was sitting but the moment I sat across from her and she was asked to demonstrate a movement with her arms, her tremor disappeared. I asked her if she had a dance background since her arms were flowing beautifully, with an almost balletic position in the fingers. She giggled and answered "No, none," and this stunned me. I wanted to learn more and began asking questions: why did these people choose dance? What are their experiences in the class? How is it that I can leave a class only thinking of all the joyful people that I just conversed with and danced with, rather than thinking about the fact that this was a therapy session for those living with Parkinson's? It was this particular experience that created this desire to research the topic further and to find out about the quality of physical activity experiences of individuals with Parkinson's.

Parkinson Canada, a leading research, support, and advocacy organization in Canada describes Parkinson's Disease (PD) as a neurodegenerative disorder, predominantly affecting those over the age of 65 years, with an estimated 55,000 Canadians diagnosed with the disease (Parkinson Canada, 2017). The disorder results from the loss of cells that produce dopamine. As such, individuals with PD experience a decrease in dopamine, a chemical integral for the brain's motor control system, with symptoms including tremors, improper balance, slurred speech, rigidity and stiffness of muscles (Parkinson Canada, 2017). In addition, some individuals with PD develop depression and/or anxiety as a result of factors such as the loss of a valued self-identity, the perception of being a burden on others, or a sense of disengagement from others (Charmaz, 1983; Kelly & Field, 1996). Due to these symptoms, Parkinson Canada highly recommends that individuals with PD engage in physical activity as part of their treatment, stating that it can improve mobility, flexibility, as well as overall health and well-being (2017). Researchers studying the effects of physical activity for those with PD have found it leads to significant improvements in perceived functional independence and quality of life, as well as many physiological symptoms such as posture, flexibility, balance, muscular strength, short step gait, and mobility (Baatile et al., 2000; Crizzle & Newhouse, 2006; Goodwin et al., 2008). Physical activity has also shown to address depression and anxiety for those with PD, with significant improvements in levels of motivation and positive mood (Ahlskog, 2011).

Given the positive effects of physical activity for people with PD, there is value in research investigating treatment programs that would ensure people with PD are participating in physical activity programs under the most optimal settings. Researchers often evaluate physical activity treatment programs for those with disabilities by measuring rates of participation, with participation being defined as "involvement in activities or roles in the community that are

associated with an improvement in physical and mental health, as well as in quality of life” (Martin Ginis et al., 2016, p.396). What is often not considered when evaluating physical activity programs is the *quality* of participation, which accounts for an individual’s subjective perceptions and experiences (Martin Ginis et al., 2016; Shirazipour, 2016). By exploring the lived experiences of individuals in physical activity programs, researchers and program developers/providers can identify elements that lead to an optimal participation experience for its target population (Martin Ginis et al, 2016).

Researchers have recently developed frameworks to conceptualize the *quality* of participation (e.g., what meanings or satisfactions are derived from the activity) rather than just the quantitative metrics of participation (e.g., how many participate in the program) (Shirazipour, 2016). Martin Ginis and colleagues’ Quality Participation (QP) model (2016) offers six themes associated with the experiential aspects of quality participation: autonomy, belongingness, challenge, engagement, mastery, and meaning. According to the model, these themes should be taken into account when conceptualizing and operationalizing the participation construct in the program of interest. The model was developed specifically for exploring the quality participation of individuals with physical disabilities across various domains (e.g., employment, general community participation, rehabilitation, physical activity) and to encompass the experiential aspects of participation. As the QP model is a fairly new conceptualization of QP, few studies have employed the model to date, and there are no known studies to employ the model in understanding physical activity experiences of individuals with PD (Martin Ginis et al., 2016). The QP model has however been applied into Paraspport settings (REF). In doing so, researchers identified that three conditions must exist within a Paraspport program for an individual to experience quality participation. The three conditions are related to the physical

environment, activity, and social environment(Evans et al., 2018) and represent how participation in a sport program for those with physical disabilities is enabled and/or supported, while the six themes represent elements of the quality participation in an activity for those with physical disabilities. This study applied the QP model to investigate the experiences for people with PD within a physical activity program and in hopes of better understanding what elements lead individuals to have a quality experience. It was chosen in large part because it is the only model that offers a conceptualization of quality participation experiences geared towards people with disability in rehabilitation (Shirazipour, 2016).

There are various physical activity programs aimed at supporting individuals with PD through Dance Movement Therapy (DMT). DMT is a practice that simultaneously engages somatic, emotional, and perceptual processes. DMT does not necessarily follow the precise technical aspects of dance; rather, the focus is on using physical movement to gain control of or help manage both motor and non-motor symptoms (Hanna, 1995). Studies examining DMT effects among people with PD found improvements in physiological symptoms including posture, range of motion and tremors (Hackney & Bennett, 2014; Houston & McGill, 2013; Westheimer et al., 2015). A recent collaboration led by York University's Centre for Vision Research found long-term benefits related to participation in the DwP twelve-week program, including improvement in balance and gait (DeSouza, 2017). Several studies have suggested that DMT also increases perceptions on quality of life among people with PD (Hackney & Earhart, 2009; Heiberger et al., 2011; Westbrook et al., 1989; Westheimer, 2008). To date, much of the research on the experiences of people with PD participating in physical activity programs which utilize DMT have focused on the physiological aspects and symptoms of the condition or perceptions of quality of life through quantitative research tools(Hackney & Bennett, 2014,

p.18). 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, or to the experiences and perceptions of DMT among PD patients more specifically. As such, exploring the experiences of the DwP participants offers a prime opportunity to understanding what comprises quality participation in physical activity for individuals living with PD patients and their subjective perceptions of the sessions as a whole.

This study aimed to understand the experience of quality participation for individuals with PD who participate in a DMT program, drawing on the QP model (Martin Ginis et al., 2016). It focused on the lived experiences of those attending the DwP program, with the purpose of better understanding how a program using DMT offers opportunity for quality physical activity participation for individuals with PD. Employing a case study approach at one of the DwP program locations in Toronto, this project examined DMT through the lens of the QP model and explored what meanings individuals with PD derive from their experiences with a program applying DMT (Martin Ginis et al., 2016).

The specific objectives of this study were as follows:

1. To explore the quality experiences of people with PD participating in DMT in the DwP program; and
2. To better understand participants' experiences in DMT through the lens of the QP model (Martin Ginis et al., 2016).

The following research questions were used to fulfill the objectives:

1. What meanings (i.e., what they find personally significant) do individuals with PD derive from their experiences with the DwP program?

2. How does the experience of the DwP program relate to the concept of quality physical activity participation as conceptualized by the QP model (Martin Ginis et al., 2016)?

The following chapter of this thesis will review relevant bodies of literature and will then be followed by an outline of the methods. Chapter Four and Five will present the results of this study, while Chapter Six will provide a broader discussion of study findings and conclusion, including the strengths and limitations of the study as well as possible directions for future research in this field.

Chapter 2: Literature Review

This literature review will begin with a brief description of PD of the chief psychological concerns people with PD may face. Included is a review of literature demonstrating the benefits of physical activity for people with PD, as well as an explanation as to why there is such need to assess the quality of physical activity programs that are offered to people with PD. The QP model (Martin Ginis et al., 2016) will then be discussed, followed by description of the DwP program that will be evaluated through the lens of quality physical activity participation. The review of literature will be followed by a detailed outline of the methods of the proposed project.

Parkinson's Disease: Common Factors Producing Negative Experiences

As noted in the introduction, PD is a chronic neurodegenerative disorder affecting one in 500 people worldwide (Parkinson Canada, 2017). PD can be considered a disability as it presents individuals with daily challenges that make it difficult to interact with their surrounding environment. According to the International Classification of Functioning, Disability and Health, (ICF), disability is the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a

health condition such as PD) and that individual's contextual factors (environmental and personal factors) (World Health Organization, 2017). Some of the common impairing motor symptoms of PD consist of tremors, decreased coordination, postural instability, and gait impairments (Houston & McGill, 2013). Whereas our knowledge of the physical and physiological symptoms of PD is now well established, the psychosocial impact and challenges of the disease still require more attention (Soundy, Stubbs & Roskell, 2014). Nonetheless, it is recognized that people with PD can develop various challenging psychological symptoms including apathy, anhedonia (the inability to feel pleasure), depression, cognitive dysfunction, and various mood disorders (Poewe, 2008).

PD can generate a range of negative thoughts and feelings including feeling like a burden on others due to immobilization, feeling isolated and undervalued, and perceiving a lower quality of life (Hackney & Bennett, 2014; Houston & McGill, 2013; Moore & Knowles, 2006). It is important to consider the experiences of individuals with PD as it has been recognized that they have a strong correlation with quality of life and treatment compliance (Hole, Stubbs, Roskell & Soundy, 2014). There are several distinct factors that can facilitate negative experiences for people coping with this disease and some of the most studied factors include: living a restricted life, lacking communication with others, and having their new definition of self be discredited by stereotypes (Miller et al., 2006; Moore & Knowles, 2006; Soundy, Stubbs & Roskell, 2014).

A review analyzing the experiences and perceptions of people living with PD found that participation in meaningful activities, as defined by those individuals living with PD, decreased considerably following diagnosis for many individuals (Soundy, Stubbs & Roskell, 2014). This decrease in participation was highly correlated to an increase in negative perceptions, moods and emotions, including depression and low motivation (Soundy, Stubbs, & Roskell, 2014). In one

study, a large portion of individuals with PD have reported feeling that they can no longer take part in hobbies or daily activities enjoyed prior to diagnoses, and, as a consequence, experience increased negative perceptions, moods and emotions (Pierret, 2003). Feeling that one's life is restricted after being diagnosed is a common factor for those with PD that leads to negative thoughts, such as feeling shame and/or being upset with themselves (Pierret, 2003). In contrast, being able to maintain activity levels or develop other meaningful activities has been associated with higher hope and well-being for individuals with PD (Soundy, Stubbs & Roskell, 2014).

Another factor that can contribute to negative life experience for people with PD centers on communication. The progressive development of voice changes or alterations in articulation that occur in 80-90% of those diagnosed with PD increasingly leads to challenges in communicating with others (Miller et al., 2006). Difficulties with conversations are also linked to other behavioural issues, including problems initiating speech movements, difficulty finding words and formulating ideas, which then makes it even more difficult for individuals with PD to enter or continue adequate conversations (Miller et al., 2006). When individuals with PD feel that they are unable to express themselves in a way that they were used to, they are often left feeling frustrated, neglected, depressed and/or disengaged from others (Soundy, Stubbs & Roskell, 2014). The struggle around communication for individuals with PD is relevant to this study as it explores DMT, a form of somatic, embodied communication, and it is important to investigate how DMT may (or may not) allow individuals with PD to attend to their communication challenges (Hanna, 1995).

Feeling stigmatized is another factor people with PD frequently face that can lead to negative life experience. Moore and Knowles (2006) surveyed public attitudes towards PD and found that greater public knowledge is needed surrounding PD as there still exists significant

stigmas and misconceptions about the disease. For example, they found that many people automatically associated PD with becoming a burden and being heavily dependent on others; something that is not necessarily true for all individuals with PD throughout all stages of the disease. The study also noted that a small proportion of the public perceive PD to be caused by lifestyle factors such as drinking alcohol, smoking or improper management of health; a factor that leads to blaming and negative attitudes towards those with PD. A significant portion of the public was also found to erroneously believe PD is a rapidly acting disease that inevitably leads to dementia and a shorter-lifespan. The negative stereotypes that exist towards PD create an unpleasant environment in which developing a secured and valued sense of self becomes difficult (Kelly & Field, 1996). These feelings of being undervalued or ashamed in the PD population can lead to depression and/or social withdrawal (Moore & Knowles, 2006).

A number of scholars posit that when a person is diagnosed with a chronic illness, such as PD, is unable to adjust to their new lifestyle, and express themselves, that person has difficulty developing a new healthy self-identity; as a result, their value of self is weakened (Livneh & Antonak, 2005; Charmaz, 1983). This can then lead an individual to perceive to have a lower quality of life and causes a lack of pursuit of social or personal goals, making treatment more difficult (Livneh & Antonak, 2005). It becomes essential to consider the factors that may create quality experiences for people suffering from PD, in order to avoid poor psychological health and to ensure proper treatment for the most optimal quality of life. It is necessary that individuals with PD have the opportunities to remain active and connected to others in order to create and support a valued sense of new self and to resist isolation or false (self-) representations of being “too ill” or burdensome (Charmaz, 1983). Therefore, it is not only important to understand the factors that can cause poor experiences for those suffering from PD, but to also explore ways to

enable positive experiences. This leads us into the discussion of participation in physical activity and its benefits for people with PD.

Physical Activity: Benefits for Individuals with PD

There is ample, long-standing and well-documented research from a wide variety of disciplinary areas that supports the health benefits of physical activity for all (Warburton, Nicol & Bredin, 2006). Particularly relevant for individuals with PD, there is a considerable amount of evidence suggesting that physical activity leads to an increase in dopamine production, thus countering the deficiency in dopamine levels that results from PD (Baatile et al., 2000). The physical benefits of physical activity for people with PD have been well documented, with evidence demonstrating increases in overall fitness, functional independence, range of motion and strength (Baatile et al., 2000; Rosenberg et al., 2011).

Although few studies focus on an evaluation of the benefits of physical activity on non-motor symptoms for people with PD, the extant literature in this topic document positive broader health benefits too. For instance, the brain has the capacity to reshape itself in reaction to self-produced activity (Hirsch & Farley, 2011). That is, physical activity can activate healthy plasticity-related mechanisms in cognition for people with PD (Hirsch & Farley, 2011). Physical activity programs are also beneficial for PD in terms of the reduction of mild cognitive impairment and, in addressing depression and anxiety, significantly improve motivation and positive mood (Ahlskog, 2011). Perceived quality of life in individuals with PD also increases when individuals partake in physical activity (Baatile et al., 2000). Overall, the studies that do

look at the psychosocial symptoms of people with PD demonstrate that participating in physical activity has noteworthy benefits.

Information on the benefits of physical activity for those with PD is substantial, but the experiences that occur throughout the process of these physical activity programs are not as well documented. For instance, Goodwin et al. (2008) reviewed 14 randomized controlled studies to determine the effectiveness of physical activity interventions on outcomes for people with PD including: physical, psychological or social functioning, and quality of life. It was concluded that physical activity led to improvements in physical functioning, strength, balance, gait speed and quality of life. However, this review was short of any information on the participants' lived experience with and perspectives on the physical activity programs for which they were recruited. Research would benefit from analyzing the subjective experiences of the individuals with PD to help understand the quality of physical activity they are experiencing, and how to further improve it (Shirazipour, 2016). This leads us into the discussion of the concept of quality of physical activity participation.

Quality of Physical Activity Participation

In order to provide an effective and positive physical activity experience for people with PD, physical activity programs and the ways in which programs facilitate or constrain participation must be explored. Participation, in the case of physical activity, is the nature or extent of the involvement in the activity; it is considered to play a pivotal role in contributing to a healthy well-being and everyday functioning (Shirazipour, 2016). Therefore, when it comes to the managing of symptoms for people with physical disabilities, participation has been recognized as a fundamental component of therapy and quality of life (Martin Ginis et al., 2016).

The majority of research that has assessed physical activity programs with regards to participation has done so using quantifiable measures, evaluating the frequency of program attendance and the total time spent involved in the activity (Shirazipour, 2016). These elements of participation can be easily quantified and measured, but do not contribute to our understanding of the experience of *quality* of the physical activity participation, nor to the meanings and satisfactions derived from physical activity. Without more focused attention on participants' perceptions and lived experiences, in their own words and terms, researchers run the risk of missing important information on what aspects of physical activity provide positive engagement. This is especially important for those with chronic disease – and in the case of this particular proposed project, for those with PD – as the benefits of physical activity are critical for health and daily functioning. Better attention to the quality of physical activity participation as well as better understanding of participants' perceptions of both their condition and their physical activity experience will help illuminate the role of physical activity in individuals' health and illness journeys.

Quality Participation Model

To date, there have been few frameworks developed to conceptualize quality of participation broadly. For the purposes of this project, the Quality Participation (QP) model conceptualized by Martin Ginis and colleagues (2016) was applied as it was the only model developed geared towards studying individuals with a physical disability participating in a various activities including physical activity. The objective of the QP model was to uncover key experiential aspects of participation for individuals with physical disabilities. The QP model was informed by a systematic review of literature that worked to operationalize participation beyond measuring

observable behaviours. The review advanced six themes that frame quality physical activity participation:

- Autonomy: Having independence, choice and control;
- Belongingness: Feeling accepted and respected at both interpersonal and societal levels;
- Challenge: Specifically, feeling and being appropriately challenged;
- Engagement: Being motivated, focused, involved and experiencing flow;
- Mastery: Experiencing achievement/competence, or having a sense of accomplishment (feelings of self-efficacy); and
- Meaning: Feeling a contribution to personal or social meaningful goals or having a responsibility to others.

All of these themes together provide a multidimensional framework that considers both personal and societal aspects of quality physical activity participation.

Most recent research on the QP model by Evans and colleagues (2018) has drawn attention to three underlying conditions that serve as pre-requisites for a quality experience for people with a disability participating in Parasport programs. This new development was considered for this paper in order to provide a more in-depth analysis of the experiences of quality physical activity participation. Evans et al. (2018) objective consisted of applying the QP model using it to generate an evidence-informed framework of optimal parasport participation. By synthesizing existing literature, constructing the framework alongside stakeholder insights, and then refining this information through an online expert panel including researchers and sport administrators, the QP model was developed further, including three pre-requisite conditions (Evans et al., 2018). The three conditions include: physical environment characteristics (ie.,

access to proper facilities, equipment); activity characteristics (ie., physical activities that are geared towards the needs of the individual based on his or her disability and individual's values); and social environment characteristics (ie., properly trained teachers, and support from family, employees, and peers). The authors suggest that it is only once the above conditions are met, that quality participation can possibly be met and the facilitation of quality physical activity experiences can be better evaluated. In other words, these conditions determine how an individual with a disability is enabled and/ or supported to participate in a sport program in the first place. Despite the fact that Evans et al. (2018) looked at Parasport settings specifically, the conditions conceptualized reflect a significant aspect of participation that should be considered when looking at activities for those with disabilities, which is why it was considered for this paper.

Though the QP model provides a good starting framework in conceptualizing quality of physical activity participation, the applicability of it is yet to be established, with very little research (to date) using the themes concurrently. Other models looking at the quality of participation do exist; however, they are not specific to the experiences of people with physical disabilities. The QP model proposed by Martin Ginis et al. (2016) is ideal for the current project given its focus on the experiences of those with physical disabilities.

Overall, it is important to examine the quality participation in physical activity programs in order to develop and maintain them, as well as to ensure the best possible experience for participants (Martin Ginis, 2016). Presently, there is no research regarding the quality of physical activity experience for those with PD, and this project focused on the lived experiences of those attending the DwP program with the purpose of understanding how this program, applying DMT, offers an opportunity for quality physical activity participation for individuals with PD.

To this end, it is valuable to briefly describe the DwP program as a physical activity program for those with PD.

DwP: An Opportunity to Explore DMT for Quality Physical Activity

DwP is a Toronto-based program with the mission “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 specifically designed to enhance and improve participants’ physical activities” (Dancing with Parkinson’s, 2015). This program applies a practice called DMT, which uses physical movement as a form of communication and expression to help an individual gain awareness of both their body and mind (Homann, 2010; Koch & Fischmann, 2011). The goal of DMT for those with PD is to improve range of motion, improve posture and gait, as well as gain perception of self; finding insight and discrediting misconceptions (Hanna, 1995). The combination of movement, rhythm and music provides an opportunity for a complex expression that involves simultaneous engagement of the body and the mind, offering a participant challenge (Hanna, 1995). Cognition is an important part of DMT as the sessions involve memory, perception, attention, reasoning and decision-making (Hanna, 1995).

DMT instructors are meant to encourage participants to develop value from their movements and to build relationships with others (Koch & Fischmann, 2011). DMT programs are group dance programs that meet on a weekly basis. They foster the development of social community and offer support. In addition, the programs provide a welcoming atmosphere as they do not focus on the disease itself, but rather focus on providing physical activity in the form of dance (Houston & McGill, 2013). Many DMT programs have high attendance and adherence rates, which demonstrate high motivation to participate (Hackney & Bennett, 2014).

In DMT, dance is not so much related to performance as it is to physical activity. The dance routines taught are rhythmical, purposeful, and are patterned sequences, offering external cues through music and a safe environment for participants to work on the techniques. Earhart (2009) offers five reasons as to how DMT can be considered a very fitting physical activity program for those with PD. First, it teaches specific movement strategies, such as how to hold proper posture. Second, it offers practice for external cues by having exercises done to music on certain beats. Third, balance exercises are always included in DMT classes, where individuals practice control of their body while being dynamic and aware of their environment. Fourth, it involves the building of both strength and flexibility. Lastly, it is a cardiovascular workout, as dance is an aerobic activity. DMT has the potential to be very beneficial for people with PD with regard to physiological and functional outcomes.

Based on existing studies of DMT, the practice has revealed to be rehabilitating for people with PD. Physiologically, studies have found that DMT has positive effects on patients' motor function, with significant improvements in posture, gait, balance, range of motion and tremors (Hackney & Bennett, 2014; Houston & McGill, 2013; Westheimer et al., 2015). Researchers looking at the effects of PD programs applying DMT found that participatory dance enhanced quality of life (Hackney & Earhart, 2009; Heiberger et al., 2011; Westbrook et al., 1989; Westheimer, 2008). In addition to physiological and functional outcomes, DMT programs have also shown to be correlated with higher self-confidence and increased motivation (Houston & McGill, 2013; Westheimer et al., 2015). For instance, Westheimer et al. (2015) found that participant adherence was exceptional and all of their participants desired to continue DMT after study completion. Houston and McGill (2013) found similar results, with patients displaying a high motivation to attend class.

As noted earlier in this proposal, while there is some (and growing) research on the benefits of DMT programs for individuals with PD, there remain gaps in our knowledge of the qualitative experiences of those participating in such programs. Research that has looked at non-motor or non-physiological dimensions of experience (e.g., quality of life, self-esteem and coping with the disease), has been quantitative in design (Strassel et al., 2011; Sharp & Hewitt, 2014). Furthermore, there is no research that has explored DMT for individuals with PD using the QP model advanced by Martin Ginis and colleagues (2016). This proposed project offers to attend to the gaps noted above and to explore the experiences of the physical activity people with PD are having in the DMT programs using qualitative methodology. In efforts to understand the experiences of quality participation for individuals with PD who participate in a DMT program, this study focused on the lived experiences of those attending the DwP program. Employing a case study approach at one of the DwP program locations in Toronto, this project examined DMT through the lens of the QP model and explored what meanings individuals with PD derive from their experiences with a program applying DMT (Martin Ginis et al., 2016). This project attended to the following main research questions: What meanings (i.e., what they find personally significant)) do individuals with PD derive from their experiences with the DwP program, how does the experience of the DwP program relate to the concept of quality physical activity participation as conceptualized by the QP model (Martin Ginis et al., 2016)? The following section will include a detailed outline of the methodology of the study.

Chapter 3: Methods

Given this project's focus on the experiences of and meanings derived by participants with PD in physical activity, this study employed qualitative research methods as part of a single-case study approach of DwP (Polkinghorne, 2005, p.138). A case study approach focuses on learning about the dynamics present within a single setting – an appropriate strategy for this project as it enabled a detailed account of research participants' experiences in a specialized program and setting (Baxter & Jack, 2008; Yin, 2003; Yin, 2013).

Participants

Participants included eight individuals (two male and six female) enrolled in the DwP program, the only established DMT program for those with PD in Toronto (Ontario, Canada). Given that the DwP classes are designed to accommodate every level and ability of the individual with PD, the severity of PD among the participants in this study ranged from mild to severe (Dancing with Parkinson's, 2015). Study participants were recruited using a purposeful sampling technique (selecting the most appropriate sample to answer the research questions), and a snowball sampling (having candidates recommend others for recruitment) (Marshall, 1996). As this qualitative study was geared towards investigating experiences of people in the DwP program, there were no exclusion criteria for recruitment such as severity of the disease, age, or gender of the participants. The DwP organization was contacted directly and asked to disseminate recruitment information to their members via announcements in class. Past and current DwP members were welcomed to participate in this study to ensure as large and diverse a pool of participants as possible; however, only current members volunteered to participate.

Data collection

Semi-structured interviews

Semi-structured interviews, between twenty to sixty minutes in duration, were conducted with study participants. Each participant attended a single one-on-one interview at a location of which was agreed upon with the participant prior to the interview. Given that this case study focuses on one specific program, great care was taken to ensure the confidentiality and anonymity of participants. Pseudonyms were employed to protect the interviewees' identities. The semi-structured interview format operated as guided conversation between the interviewer and the interviewee, thus allowing interviewers to address specific dimensions of the research, while at the same time leaving space for the interviewees to offer unanticipated insights and/or new directions for study as part of an in-depth account of their experiences (Galletta, 2013, p.2). The interviews were taped using an audio recorder, and notes were taken during and after the interview. Interviews were transcribed verbatim.

The interview questions were open-ended, providing participants with opportunities to direct dialogue and, ideally, feel more free and open with their responses (Hermanowicz, 2002; Warren & Williams, 2008). Given the focused nature of this case study, the results of this study are not necessarily representative and/or generalizable to other DMT programs specifically, or to other physical activity programs for participants with chronic disease, more broadly. Rather, the interviews offered a better understanding of the physical activity experiences of the study participants who engage in the DwP program, and their beliefs on what constitutes quality participation for those with PD in a DMT program.

A semi-structured interview guide (see Appendix C) helped guide the interviews. The questions and follow-up probing questions asked were designed to explore participants' physical activity experiences and were guided by the QP model. The questions were developed using the sample questions provided in earlier research pertaining to the themes in the QP model (Martin Ginis et al., 2016; Shirazipour et al., 2016). The questions were geared to understand the individual's experiences in terms of the six themes presented in the framework including: autonomy, belongingness, challenge, engagement, mastery and meaning (all discussed earlier in the proposal). A sample question for the theme of challenge (to be appropriately challenged) would be, "Do you feel you can easily engage in the DwP activities?" As the interviews are semi-structured, the questions posed may have been altered in form or order based at the time of the interview based on the responses of the interviewees. The purpose of an interview guide in semi-structured interviews is to help move the interview along; it is "not an inflexible list that the interviewer follows rigidly" (Hermanowicz, 2002, p.485). This format facilitates more natural conversation between the researcher and participant while also keeping both interviewer and interviewee centered on the study at hand.

Analysis

Thematic data analysis was employed in this study in efforts to ensure that relevant themes emerge from the participants' descriptions of their experiences (Fereday & Muir-Cochrane, 2006; Schmidt, 2004). The recorded interviews were transcribed verbatim. Transcripts were then read and re-read in order to identify themes and patterns in the responses from and across the interviews in relation to existing research, with focused (but not exclusive) attention to the QP framework conceptualized by Martin Ginis et al. (2016). Thematic analysis procedures outline the development of initial codes from the transcripts and then subsequent categorization

of those codes into potential themes (Fereday & Muir-Cochrane, 2006). Specifically, open codes were first created within each interview by identifying individual meaning units representative of each participant's experiences. These open codes were then connected and organized into overarching themes and sub-themes. These key themes were then further developed and refined. Once the themes were established from the codes, a more detailed and holistic analysis commenced and the themes were related back to the original research questions (Galletta, 2013; Yin 2003; Yin, 2013). Dr. Celina Shirazipour, was contacted in order to provide an additional perspective during the coding phase of the analysis. Having worked on several projects that incorporate the QP model, including a study on veterans (Shirazipour, 2017) and in collaboration with Evans et al. (2018), Dr. Shirazipour offered a great source of expertise with regard to the model. Dr. Shirazipour clarified the QP model and the process of analyzing data, as well as co-coded two of the interviews to serve as examples of this process. For the most part themes determined by Dr. Shirazipour and myself were similar. The only divergence in coding came from the importance participants placed on relationships with the instructors. The question became whether this data should be described as a condition that enables participation or as a part of the experiential theme of belongingness. The mutual decision was made considering relationships with instructors as an essential experience of belongingness leading to a quality experience for the participants.

Ethics, Approval, Confidentiality and Informed Consent

The project was approved by the ethics review as outlined by the York University Graduate Student Human Participants Research Protocol. Participants were recruited after formal approval was received by York's research ethics office. All information collected in the research process was used in confidence, with pseudonyms used for every interviewee to protect the

anonymity of the research participants. Any references that may have identified participants, and/or specific situations and locations, were altered. Participants had the option to view their transcripts for the purposes of verifying the interview record; none of the participants chose to do so. Sufficient time was offered to participants in case they would like to review any of the statements contained in their official transcripts. Transcripts and recordings of the interviews were stored on a password protected hard drive only accessible by the researcher. The researcher and supervisors were the only individuals to review drafts of the thesis.

Though no risks or discomfort were foreseen from the participation in this study, due to the nature of PD, participants were ensured a safe and comfortable environment. Furthermore, participants were consulted as to whether they required or wanted the involvement of or assistance from their caregiver during the interview if they felt this might enhance their comfort and convenience. If such assistance was requested by the participant, arrangements were made prior to the interview. Furthermore, if requested by the participant at any point in time in the study, contact information for support resources from Parkinson Canada was made available.

Information on the confidentiality provisions and the nature of the research was provided to the participants to the fullest extent possible, without putting at risk the confidentiality extended to any other research participant. The participants were fully informed prior to the onset of the interview process and were provided with a copy of the Study Information Sheet (Appendix A). Participants also signed an Informed Consent Waiver that outlined their participation was voluntary and confidential, and that they may refuse to participate in the research, or withdraw from the project, at any point during the research without penalty. Each participant was required to sign two copies of the Informed Consent Waiver (Appendix B), with one copy being kept by the researcher and the other returned to the participant.

Methodological Experience

Before commencing my research on DMT and the DwP program, I had been both a professional ballet dancer and a volunteer at DwP. My personal experiences with dance and the DwP program are what motivated me to investigate these areas and conduct this study. Due to my involvement with the program, and my personal connection with dance and dance as a therapy, I felt it was necessary to provide myself with the opportunity to reflect on my role as a researcher during the process of data collection and analysis. A reflexive journal was kept throughout this study, in form of audio recordings, where the aim was to be self-reflexive about my interpretations of the participants' perceptions and experiences, based on what they had shared with me. By being reflexive, there is an ability to take a critical look at my own role in the research process, thereby improving the quality and validity of the research, and recognizing the limitations of the knowledge that is produced (Guillemin & Gillam, 2004). In what follows, I will reflect on my experiences in an effort to illuminate my personal reasons for becoming interested in the topic of dance therapy. Through this, I will explore how this research affected me and how my perspectives consequently shaped the study.

My Experience with DMT and the DwP Program

I cannot say that my pursuit of a ballet career did not come with its rewards and benefits, but it was one that made it difficult for me to develop a valued sense of self and personally meaningful goals. In the years leading up to me discovering the DwP and DMT, I was a burnt out ballet dancer. I was passionless about my work, I had no motivation to improve or even continue with the career. After a couple of years of being in this state, I finally reached a point where I wanted to step away from dance as a whole and steer my focus more seriously into the

world of academia. Nonetheless, my attempt to escape dance completely did not work out as planned, and for the better. After holding conversations with various people who held high statuses (in my view), in academia and in the medical world, I was convinced that a successful academic path for me would be to combine my newly gained knowledge in psychology and my past experiences of dance together. One woman in particular really pushed the idea of combining psychology with art, and she introduced me to the DwP program where I would eventually become a volunteer.

After witnessing just one session, I was instantly inspired by the program. I enjoyed seeing how people left the session with happy faces and energetic moods, and how I felt the same. Most importantly, the concept of choice, the choice that the people with PD got from the DwP program, fascinated me. I admired the DwP for its ability to provide, not only a space where individuals could dance but where these dancers could move however they liked. This freedom gave me pause and I found myself reflecting on why this element (i.e., choice) was so resonant for me? After reflecting on this, I realized that through my career as a dancer, despite being able to move as I pleased, I had lacked the experience of making meaningful choices. My pursuit of ballet as a career provided me with strict guidelines that I was to abide by in order to succeed. After years of following these rules, I felt I lacked freedom and never developed my true self and, in turn, began hating dance. With the discovery of the DwP program, I was introduced to the idea that dance can be freeing. Since my participation with the DwP, I slowly learned to use dance as a tool to express myself, finding energy, motivation and meaning in my dance movements. A major turning point for me was allowing myself to make the choice of how I was going to dance and how I want to dance. I was inspired by DwP as a dancer and this sparked my interest in dance therapy. While DwP transformed me personally (back towards

dance and newly towards dance therapy), it also connected me to the participants in DwP class and the next section turns to the research challenges and opportunities afforded to me by my newly formed DwP insider status.

My Research Experience

Understanding the importance of feeling in-control, and having choice in one's life and feeling value in one-self, connected me to the very central questions of this study. With my own sense of what I find meaningful about dance, I became curious to find out what others felt was meaningful to them about dance and dancing. I felt connected to the study participants because of our shared pleasure with dance and dancing and I felt as though this shared relationship with dance allowed me to probe freely during our interviews together. Understanding how dance helps me, I found I could ask if this was similar or different for the participants. My experience of lacking choice and then gaining it through dance, made it easier to find questions to ask the participants, as well as to understand certain emotions or memories participants may have brought up, which made probing for answers, surrounding the topics of meaning and choice, easy to do.

Another benefit of our mutual pleasure of dance and dancing was that I was able to build strong rapport with the participants. I have no doubt that my volunteering with DwP as well as my own dance background contributed to their comfort with me. They appeared to be open to discussing their experiences with dance and talking about dance without needing to explain certain moves or aspects of the class. Before recruiting participants, I would explain that this research would also serve to benefit the participants, as it would investigate aspects of the program that could lead to further improvements and understanding of the mechanisms of DMT.

Acknowledging that I was a dancer working on making their program better, created a relationship between me and the participants where the mutual goal was to explore DMT and how it helps people. During the interviews, it appeared that the participants were supportive of my dancer-researcher identity and were more than happy to share information with me. Some participants, after the interviews were done, began asking me about my dance background and were curious to understand why I got interested in dance therapy. Having built this rapport with the participants and having mutual goals and interests enabled, I believe, very open, free-flowing discussions.

Despite my passion for the topic and my ability to build rapport with the participants, my connection with the participants was restricted. As someone who has never experienced motor-control issues nor had any close relatives with PD, my understanding the experiences the participants had shared with me was limited to what information about their experiences with PD that they shared with me. While I could connect easily to discussions of dance, I didn't share that same sentiment when it came to discussions of disability. Most participants were more than open in sharing their memories and stories. Nonetheless, I would often feel that many of the study participants avoided discussing their illness or disability in great depth; at times, it felt to me that if the topic of conversation veered away from their PD experiences outside of DwP, participants would either answer abruptly, end that part of the conversation, or discuss it in a negative way. As a nascent interviewer, I often found myself not probing those questions further with my participants – rather, I would let the question fade or ask a new question that would pertain back to their experiences with dance. In reflecting on this feature of my conversations with my participants, I could sense that I was fearful of disrupting the rapport and comfort zone that I had established with the participants. I was also aware though too that my sense of being an able-

bodied dancer made it difficult for me to feel at ease asking questions pertaining to disability, something that did not pertain to the main research questions. In general, the fact I am an able-bodied dancer interviewing participants with disabilities made me feel as an outsider and held me back from engaging with my participants during the interviews (and perhaps even with the data) to more fully understand how being disabled and living with visible motor control issues, effects a person's experience and relationship with dance and dance therapy. This insight about my own hesitancy of being an able-bodied researcher studying disability does not detract from the study but certainly offers a great deal of food for thought for my future research into dance therapy for persons with a disability.

This study aimed to understand the experiences of quality participation in programs applying DMT or those with PD. The remaining chapters will examine and discuss the patterns that were detected in the responses of the participants, as well as some of their implications. Chapter Four will focus on the three foundational conditions captured by the QP model (i.e., physical environment, activity and social environment), and what aspects of these conditions in particular are enabling the individuals with PD to participate in the DwP program. With the development of the three QP conditions during the process of this study, I found it necessary to devote a section to understand how the individuals interviewed were enabled to participate in the DwP program, before discussing what encompasses their quality physical activity experiences. Chapter Five will then consider the two research questions posed in this study and present the experiences participants valued the most from their participation with DwP using the six themes presented by the QP model. The results offered in these two chapters will then be discussed in the concluding chapter of the thesis.

Chapter Four: Conditions Enabling and Supporting Participation in the DwP

The objectives of this master's project were twofold: 1) to explore the quality experiences of people with PD participating in DMT in the DwP program; and 2) to better understand participants' experiences in DMT through the lens of the QP model (Martin Ginis et al., 2016). However, once formal data analysis was complete, and given the new conceptual developments brought forth by Evans et al. (2018), it became clear that attention first needs to be paid to the conditions that may facilitate or constrain participation for persons with a disability prior to delving into the experiences of participants in DwP specifically. This chapter focuses on examining the conditions that enabled and/or supported participation in the DwP program for the participants in this study; physical environment, activity and social environment. In Evans et al.'s (2018) research, the three conditions include twenty-five precursors that support quality experiences for those in Parasport programs. For instance, the physical condition includes four precursors: physical accessibility of facilities and services, travel and access, safe places, and access to equipment. In this study, the precursors presented align with the findings of this study, however, not all of the twenty-five precursors were met. More specifically, participants in this study valued the physical accessibility of the DwP program, the affordability of the program, the dancing and the music offered by the program, and the inclusive social environment. The physical environment of DwP enabled participation as the facilities and equipment were considered accessible for the individuals with PD. The nature of the activity provided by the DwP was considered to be valued by the participants, thereby supported their participation in the program. Lastly, the social environment, formed by the instructors and the peers, was an important factor in facilitating participation for the participants. A more detailed discussion of the above findings and how they enable or support participation in the DwP program will be provided below.

The Physical Accessibility of DwP

The desire to engage in a physical activity depends heavily on whether the program's location and facilities are deemed accessible (Troost et al., 2002). In other words, without appropriate access to safe and accessible programs for individuals with PD to be physically active, the choice to participate in physical activity becomes difficult if not impossible (Troost et al., 2002). A crucial factor for the participants in this study in determining whether or not they would attend DwP classes was the physical environment. All eight participants agreed that the DwP program is a physically accessible program for them with regards to geographic location, space of the studio, as well as availability of appropriate equipment.

The DwP classes, which the participants attend on a weekly basis, provided them with all the necessary accommodations needed in order to make their visits to the classes trouble-free. This included proper equipment as well as properly-trained staff available on-site. In general, the classes themselves did not require any specific equipment other than chairs. When asked what sort of equipment is expected to be present in the DwP sessions one participant, Ramona replied: "That doesn't matter too much, as long as there is room for us to move." Stevie added to this idea explaining that, simply, a big space is enough for the DwP sessions:

The room we're in is just about big enough for us all when we're all there. We do have to make sure that there is room so we're not bumping into the next person, and as you've seen there's a lot of movement going side to side and back and stuff. So, in terms of looking for ballet barres and mirrors [typical equipment found in dance studios], it is not what's necessary.

Having appropriate equipment was not a concern for the individuals interviewed as the dances do not require anything but the individual. The availability of space where DwP classes take place was the only physical aspect mentioned by participants as being important in making the class space comfortable for them, and this factor was deemed to be satisfying their needs.

The participants in this study all attended centrally located DwP classes, allowing transportation to these facilities to be fairly easy. The participants travelled to their DwP classes using either government-paid transport, public transport, or by walking. The only problem outlined in terms of transport to the DwP sessions was parking, with either a lack of accessibility to parking available at the locations or with the price of parking being considered unreasonable. For instance, Pip stated, “I don’t know why you have to pay so much; parking should be free for people who are handicapped you know?” Based on the participant responses, the DwP program provides the accessibility needed through the practicality of its facilities.

The DwP Activity: Affordability, Dance, and Music

Along with the DwP program being considered physically accessible for those with PD, the participants described three additional features of the DwP program that they felt facilitated their participation in the program: 1) the price of the program; 2) the core physical activity of the program: dance; and 3) the importance of music. These three characteristics of the DwP activity are considered to be the factors which encouraged the participants’ desire to take part in DwP classes.

The first characteristic of the DwP activity that made this program accessible for the participants was the price. The DwP itself was found to be very affordable, with each class being between \$10 to \$12 per hour, depending on the location. Stevie explained that the combination

of a therapeutic dance class with an affordable price was great for her: “I guess the positiveness is just feeling good about yourself and your body, and you know, what more can you ask in an hour for \$10?” For these participants, the affordability of the DwP program rendered it accessible and viable for them – it ensured that they would, at the very least, come to the studio rather than dismissing the activity outright. Given the small number of participants in this study and the fact that none of the participants identified the price of the DwP program as a constraint, with the exception of the complaints about the price of parking, we must be cognizant that even \$10 to \$12 per hour may be a barrier to others with PD. DwP is not a program that is free to all and therefore this may have implications on who is able to participate. The individuals in this study all chose to participate in DwP and were willing to pay the fees; this already indicates a certain measure of interest and engagement with the DwP program.

The second facilitating or supporting characteristic of the DwP program was that dance, in and of itself, was valued by the participants in this study as the physical activity that they wanted to participate in. It is important to acknowledge that all the participants recognized the value of physical activity in their daily lives. While the degree to which the participants engaged in physical activity prior to the DwP program varied, all the participants communicated their understanding that physical activity is ‘good for you.’ Prior to being diagnosed with PD, five of the eight participants engaged regularly in physical activity in their daily lives. For instance, George explained: “My main love was hockey. I always looked forward to the winter for that primarily. And skiing, I love skiing. And unfortunately, I can’t do that anymore.” Other participants admitted that their physical activity level has always been minimal and usually constrained to walking, like Bridget, who said: “We like to travel, we travel quite a bit, and we do short walks. But I actually wasn't doing much exercise.” When participants were asked why

they first chose and continued DwP classes, one of the main reasons was the acknowledgment that physical activity is good for them, particularly for PD. The participants were aware of the importance of movement and keeping their body and brain active – this understanding was either learned through personal research or through their doctors' prescriptions – and they began attending the DwP program to ensure that they are physically active. Two of the participants have been attending the program since the program started ten years ago in 2008, while the others have been going for only a couple of years or months.

When asked about dance specifically, all the participants responded positively, valuing dance as a physical activity that suits their needs. Pip describes dance as “very good. Very stimulating. I like to dance.” Similarly, Bridget explains: “Oh it’s great. Like I said, I used to do it when I was in my 30s, so I think it’s great exercise” Some participants mentioned the fact that their prior participation in other dance programs contributed to their desire to take part in DwP. For instance, Stevie stated: “Not that I did ballet for a lot of years, but what I’m enjoying with these DwP classes is the aspect of incorporating things like ‘ronde de jambe’, and some of the other ballet movements. I like that because I think I can feel my body kind of reawakening.” Pip also danced for several years prior to being diagnosed, explaining that this is one of the reasons she enjoys the DwP classes, further explaining: “it makes me feel nostalgic.” Some of the participants had never danced before but they too communicated their pleasure with dance as the activity. For example, Leonard, who explained: “Dancing is not something I did. I surprised myself by agreeing to do this.”

All of the participants in this study saw the DwP as a valuable means to keep their bodies engaged in movement. Bridget said: “Sometimes I just don’t have much energy to push myself to do anything, so when you have a program you have to go to, it’s very helpful.” George echoed:

“You see some guys in a wheelchair get up and dance and, to me, that’s incredible. I know for myself if it wasn’t for the surgery I’d be in a wheelchair by now, and if I could I’d still find a way to come.” Others, like Brenda and Leonard explained their choice more specifically, saying they chose the DwP due to its ability to engage the brain as well as the body. When asked to describe a favorite memory of DwP, George answered:

There was one day we were doing mirroring, and the music they were playing was very slow and a melancholy type of song. And we were told to think back to a feeling we had in class when something didn’t feel quite right. And I felt it personally. I was able to bring out this memory and transfer it into the exercise we did that day.

In this instance, George describes a moment where his mind and body connected in dance.

The music played during the DwP exercises also figured as valuable for the study participants. Ramona explained: “Music makes all the difference, I hate exercising to no music. I used to be able to go for long walks and things like that, but as for gym [grimaces].” Leonard also found music important, describing his ideal exercise routine as: “Something that where the music has a good beat, to keep up with the rhythms and the motions.” In general, the participants referred to the DwP music as “fun” and “dynamic,” and described the music as persuading them to be more engaged in the classes. Bridget explains that what makes classes fun for her is: “The variety, the music, the enthusiasm; the variety of music she [the instructor] plays.” The dynamic nature of the music, described by the participants as always changing and ranging in genres (from rock and roll to the instrumental classics), contributed to the DwP participants’ feelings of high energy and desire to engage in class. Live music was played in most DwP sessions and participants noted this as a factor that played a role in their desire to attend class.

Most of the individuals interviewed mentioned participating in other physical activity programs or other PD-related groups, such as boxing, singing, and physiotherapy. However, all felt that the DwP is a program worth attending as it is one of the few social programs in Toronto providing physical activity to engaging music. Ramona mentions that she does not participate in anything but DwP because she enjoys the music and finds it fun, when asked if she knows about any other programs that include music she answered:

Ramona: “There is this thing called Dancercise and I think they have an exercise to music, but I never got to explore that since I got Parkinson’s.”

Researcher: “Okay, and how come you wouldn’t explore that now?”

Ramona: “Because I’ve got DwP.”

For Ramona, DwP offers the right mix of physical activity and music that she likes, and therefore she does not feel compelled to seek out other programs.

Other participants explained a similar feeling, with the DwP music providing the major difference in their desire to participate. For instance, Leonard explains that even though he does attend another class that is similar to DwP, the major difference for him is in the live piano music. He explained that the music in the other activity is “often too loud hard rock” and that he prefers “classical, pop, and folk.” Adding that at DwP, “the music has definite beats to it, and we do definite motions to it. Like tea for two [a piece of choreography done in class]”. Pip also prefers DwP music: “It’s more gentle, other stuff is more heavy.” Another participant, Bridget, explained that she likes DwP music because it has been choreographed to, saying: “Other exercise classes are also very good with this 1 to 10 repetitions, but there’s no choreography. The

choreography is good for your brain and I like that.”For the participants, even though there is awareness of other programs with similar activity characteristics, the DwP offers them a combination of music and movement that they prefer over the other programs.

Another aspect of music valued by the participants was its ability to stimulate positive memories for them. When asked to recall a positive memory of class, many of the participants mentioned dances choreographed to songs that they connected with. Ramona recalled: “Oh last time in class they played an Irish jig, and that was something my mother taught me when I was a child and after we finished the class, I started jigging, which is quite surprising. And it brought foot movements and I was surprised to find that I could [follow the choreography].” Not only did the song bring back memories, but it also led to movements that surpassed the participant’s expectations. Elvira explained that that what makes DwP enjoyable for her is the music played during class makes her reminisce of the past: “It makes it fun. So, like when she brings out a song you know that you never hear anymore and they bring them out.”She further described: “Well, we had Elvis Presley, that was kind of fun, brings back your music, the good times.”For the study participants, the music played in the DwP classes reminded them of the “good times” and, invariably, this feature added to their positive association with the DwP program and their decisions to continue participating. Interestingly, there may even be a physiological connection here that is of note as other studies (e.g., de Dreu et al., 2012) have documented that dancing to music may distract an individual from negative sensations, such as fatigue or pain.

Despite having differences in their reasoning behind choosing dance as a physical therapy, all participants found that the DwP program met their needs as a method of being physically active. Once again, it is critical to be cognizant that although all the study participants valued the DwP program and valued dance as the central physical activity in which they engaged

their bodies and brains – their investment into the program and activity indicates that this condition was met for them and therefore allows us to further evaluate the DwP program as quality physical activity – this study did not recruit nor include those individuals for whom physical activity or dance were less meaningful or meaningless.

The Social Environment: Positive, Professional Instructors, and Emotional Safety among Peers

The social environment is the third condition identified by Evans et al. (2018) as a necessary precursor to quality physical activity. For the participants, the social elements that enabled and supported participation in the DwP included the staff's positive personality, their sense of professionalism, and the atmosphere of emotional safety that arose because of DwP participants all had PD. Let us turn to each theme in turn.

In this study, the DwP staff were mentioned as a reason for continual class attendance and participants were particularly fond of their positive atmosphere they created through their words, actions and demeanor. Of the instructor, Leonard noted: "She is very charismatic and actually, this is all the volunteers and teachers. They are all very caring people, and the feeling I get when I come here is good." Brenda described the volunteers: "I just find the volunteers particularly delightful people of all ages. They have lots of empathy, and I don't know if any of them have any relatives or friends that have Parkinson's but I find that they're very special people." Likewise, Pip states: "People are nice. [Dance instructor] is really nice, and very accommodating." The participants of this study mentioned the staff only in a positive manner, finding them to be caring, engaging and fun. These positive attributes described by the participants not only make the DwP staff well-liked but highlighted a reason why the participants

attended DwP classes. Being around people who are deemed to be positive has demonstrated to be effective in breaking the barriers to participation for those with disabilities (Milner & Kelly, 2009; Reeve, 2006). With the DwP instructors being considered positive and approachable, the social environment of the class became comfortable for the participants.

The participants spoke to the ways in which the DwP instructors and volunteers created an inclusive atmosphere in the classes through their enthusiasm and social engagement with participants both during classes. Stevie said:

I think the atmosphere is positive and it's fun, kind of funness, which isn't a word but anyway. There's a feeling of fun that permeates the room and that's definitely 80% initiated by the instructor and then the other 20% I think is from us sitting there. You can tell some of the people are not keen on doing some of the exercises, but they'll do it anyway, and kind of just laugh.

Participation is enabled, according to Stevie, because the social atmosphere the instructor creates allows her, and others, to feel enjoyment. By mentioning the fact that some people are not always eager to perform exercises but still do it, demonstrates to Stevie that the instructors have a skill to make the DwP class comfortable enough for people to step out of their comfort zones. Bridget also explained that she likes the classes because of the atmosphere her instructor establishes, attributing it to her personality: "Her enthusiasm, I think she gets us all pepped up". Another participant, Brenda, explained that the instructors have an ability to make others feel comfortable, in particular her instructor who she describes as having a relaxed way of teaching: "I just find Joanna especially, she's self-deprecating in her sense of humour. She'll be showing us something and then she says 'Help me here, I forgot about what did we do, what are we doing next?' You know she's not puffed up about herself." Brenda finds the instructors make everyone

feel at ease and this helps them to enjoy the DwP program. In general, the social environment was deemed by the participants of this study to be friendly and energizing, and this was often attributed to the instructors.

Not only were the instructors' personalities mentioned to create an inclusive environment, but so was their professional behaviour in terms of teaching class. The creator of the DwP program in Canada, Sarah Robichaud, in particular was often mentioned by the participants as being technically skilled as an instructor, and she is the first Canadian to become a registered Dance Therapist. Other instructors in the DwP program have all been professional Ballet dancers, and have been asked by Sarah Robichaud to instruct certain classes. This professional status was important to the participants, providing them confidence in their instructor's ability to teach class. George explained that the instruction provided at the DwP is an imperative factor for him: "Just her ability to teach dance, to take a dance move and break it down to its basic function and teach it, it makes it fun. The whole structure of this program, it really helps the Parkinson's people." The skills of the DwP instructors were constantly recognized to be of high quality by the participants and it was these dance skills, in combination with the instructors' enthusiasm and support that made participants want to return to class. Stevie made a note of this at the end of the interview when she stated:

I would hate to see the program watered down and water down in terms of what's offered, and who it's offered by. I think the fact that each of these people has, I'm assuming, has gone through the National Ballet School or some aspect of that. I would hate to see that watered down by saying 'Yeah, I teach a fitness class, I'll come and do your Saturday mornings', because, in a sense, this really isn't a fitness class. I guess it is, but it is so tailored to the needs of the people that come to the class, that I think it's very special and

I'd hate it to lose that aspect.

To Stevie, the instructors were trustworthy, knowledgeable professionals and this factor contributed to her feeling comfortable enough to participate in the DwP classes. Similar to Stevie, Leonard notes that he trusts the instructors due to their qualifications and training, which he further describes the instructors by saying: "From what I know, the assistant that is at the Thursday class is a yoga teacher, and she has other certain qualifications, and she is being accredited for the DwP class. So, it's good. Most of the teachers have previous experience in dancing." It was evident to Leonard that the instructors were professionals, and this professionalism is significant for him as it enables him to be confident in the instructions provided during class, and not worry about participating in an activity that does not provide the most beneficial activity.

For the participants, along with positive and proper instruction, another social element that enabled and supported participation was that the DwP program provided an environment where they felt emotionally safe. Feeling emotionally safe in a group setting means that one feels that they are a legitimate member of the group, and that the group is supportive, accepting, and providing participants with an opportunity to be themselves (cf., McMillan, 1996). For DwP participants, this emotional safety is derived in part from their interactions with the instructors and volunteers but, to a larger extent, from their interactions with other participants with PD in the DwP program. This is well illustrated by George who explained that since he could no longer participate in skiing or hockey due to their PD but desired to remain active, and that the main reason for his choosing the DwP program was for its "safe environment." When asked to explain why he called it "safe," George said:

I guess in the sense that no one would ridicule you for if you do something foolish or if

you can't do a particular thing. [Pause] Well back before the diagnosis, back in the 80's, I tried the yoga, and I tried the aerobics. In those classes I felt like I had two left feet. So that's why I was reluctant. But I found in these workshops and the classes no one makes fun of you. There is this whole group of people who have the same issues as you basically, they all have Parkinson's. In one form or another, we have the same thing, and we're dealing with it in a fun and safe environment.

The fact that the DwP is comprised of people who all have PD made George feel free from judgment because he believed all of the participants were going through similar issues and, in turn, this contributed to his feeling of being understood. Stevie raised similar themes when she said: "When you get down to it, an unconscious feeling of 'It's okay.' You can't help but notice who is worse off than you are physically, and that every one of them has gone through, and is still going through a lot of emotions that I had. And I guess these classes and the people in them really unconsciously are helping each other by being there." On a similar note, Pip explained that she likes attending a class where others have motor disabilities: "It makes me feel that I'm not the only one, you know, that other people like me." For the participants, despite the differing severities of PD or the different level of dance skill, the DwP program provided an environment where there is a feeling of judgement-free connection among the participants.

The sense of judgement-free connection, and the benefits that arose from it, came through numerous times throughout the interviews. For example, some participants spoke to the pleasure they felt when they perceived that a fellow dance student was improving as a consequence of DwP. Stevie described: "It's interesting because really when I first started there were a couple people basically in chairs, you know, not moving. Now one lady who sat in an electric wheelchair thing, she now joins us by standing. It's nice to see that progress." Another

participant, Brenda, mentioned being inspired by other participants: “There was one man who was almost on his knees, looking at his ankles. That’s the way he would stand when he got out of the wheelchair and now you can see his face. He’s still bent a bit, but he is on his way up, so to speak, and I found that heartening.”

This idea of being surrounded by people going through the “same things” was often found to be a significant part of the DwP program for the study participants. Elvira noted: “They had a woman, she used to be with us and she was very bad, shaking in the motion and I find with, with there all of us together and some of us are like the ones that can’t speak, they can hardly walk, but I feel like we are all equal, we’re all the same.” When asked to describe their favourite part of class, Leonard answered: “What I take home with me is the thing we finish with, us in the circle holding hands. And we’re bowing to each other. Sounds corny, but it's a sort of an emotional experience. It seems like there’s a bond by only hands. I find emotionally we are connected at that moment.” Stevie also raised this class-ending moment as powerful for her: “And even if you're not standing up at the very end when you say goodbye, you’ve got hands to hold on each side of your body, and that's encouraging. So you know you don't feel like, the odd man out.” The circle, the holding of hands, and the bows to one another underscores, for the participants, the sense of judgement-free connection, if not outright equality, between everyone in the DwP program.

To conclude this chapter, the three conditions, physical environment, activity, and social environment were presented in order to reveal how the individuals of this study were enabled and supported to participate in the DwP program. Though not part of the original research questions for this study, the analysis of the data made it clear that we must first recognize the conditions that framed the participants’ ability to participate in DwP before then delving into the

quality of their experiences in relation to the QP model. The following chapter returns to Martin Ginis and colleagues' QP model in relation to the participants' experiences in the DwP program.

Chapter 5: The Connection between Meanings derived by the Individuals and the QP Themes

Whereas the preceding chapter identified the conditions necessary to enable participants to engage in physical activity, the proceeding chapter refocuses on the specific research questions posed in this study: What meanings do the DwP participants derive from the DwP and how does DwP relate to the concept of quality physical activity participation as conceptualized by the QP model? In particular, this chapter will focus on three themes of the six (autonomy, engagement, and belongingness) that were found to be experienced by the participants the most and that were most related to the QP model. In fact, one of the central takeaways from the data was the thematic overlap, and this chapter will outline how the meanings expressed by participants reflect the experiential aspects presented by the QP model themes.

One example of thematic overlap is with participants finding great value in having choice in how they dance and being supported by their instructors to do so, and this freedom of choice relates to the experience of autonomy in the QP model (defined as having independence, and feeling in control; Martin Ginis, et al., 2016). Another example of the thematic overlap revolves around the DwP participants' appreciation of being able to concentrate on the dancing during class and nothing else. In relation to the QP model, we can understand this immersion with the DwP activities as associated to the QP model's theme of engagement, an experience of flow, motivation, and focus. The third meaning uncovered for the participants of this study was the relationship they have built with their instructors. This relationship was closely connected to the

theme of belongingness presented by the QP, which is feeling accepted and respected in a group setting.

Not all themes from the QP model were directly involved in leading to a quality physical activity experience for the participants. The QP themes of challenge and mastery played a role in enabling the experience of engagement, but did not directly influence a quality participation experience. Meaning, a contribution to socially or personally meaningful goals (Martin Ginis et al., 2016), was also not noted as an experience that was part of a quality experience for the participants in this study. Therefore, the following sections will provide more detail about the themes that were found to influence the satisfaction and enjoyment of the DwP participants, which were autonomy, engagement and belongingness.

Autonomy: Supporting Participants to Move in the Way they Want

Autonomy is defined in the QP model as experiencing independence, choice, and control (Martin Ginis et al., 2017), and this was established as a vital feature of DwP for the participants in this study. It is critical to highlight that, for study participants, autonomy was not understood or experienced by the DwP participants as complete freedom or functional independence per se (cf., Agich, 1990); rather, autonomy was defined by their ability to make meaningful choices about their own bodies and bodily practices in class. This was critical for these individuals for whom PD is reducing their independency, via the growing lack of control over their movements. The participants' decisions in movement were not overridden by the instructions of the dance teachers. Instead, the instructors simply guide them with ideas and options of movement and then it was up to the participants to decide how they want to implement the instruction, allowing them to express and develop their own individuality. Since their conditions require

acknowledgment that not all movement is possible to execute, the instructors maintained their focus on participant safety. The idea of “do what you can” made the class, as the participants described it, “relaxing” and “fun.” Pip described her choice to come to the DwP due to her positive mood after class, saying: “My whole being feels happy because I am able to exercise.” Elvira similarly described her participation in class as: “Whatever you do is right. If your left leg is not going to you or your right leg, it’s no big deal, as long as you enjoy yourself.” The participants were attending the DwP to be physical active and having the ability to be autonomous through their execution of movement, while feeling secure in their safety, appeared to contribute to a sense of quality participation.

The participants valued the fact that they were not pressured to do exercises in a way they felt uncomfortable with. They wanted to decide for themselves at what level they would perform exercises at and how they would perform them. Stevie described the program as “safe and positive,” explaining: “It’s okay that you don’t have to have been performing at your top-level, I mean, whatever it is. I think most of us are trying to just get a leg in the air as opposed to, you know, doing it with grace.” Elvira similarly explains liking the notion of moving without being told how to move exactly:

It makes you feel comfortable that you’re not pushed to anything you know you can’t do.
You don’t have to move your right foot and your left in the same way, you know it exists.
It’s relaxing in a way that you’re not put like on the spot, or making you think that you can’t do it. You know, there’s no, ‘You have to do this.’

The participants felt as though they were not pressured to ever perform out of their comfort zones, allowing them to make the choice of how far they want to push themselves in the

exercise. The value placed on the ability to make choice without pressure from others demonstrates how the feeling of autonomy is meaningful for the participants in this study.

The importance of feeling autonomous for those suffering from disability has been established in prior research on disability, illustrating that providing personal choice plays a crucial role in establishing a positive sense of self for an individual (Grobe & Zola, 1993). One example of such a study is by Shirazipour (2017), who applied the QP model to analyze the experiences of veterans who felt it crucial to have choice in the level of their participation during the dance sessions. In this study, the DwP participants enjoyed having no strict demands on performance quality and no pressure to dance without wanting to. The participants were provided with the conditions (physical, activity-specific, and social) to be active and, with guidance from the instructors, were enabled to move in ways were comfortable for them. Ramona mentions an experience with a volunteer in the past that demonstrates how lacking the ability to make decision in her movement created a negative experience for her. She explained: “One thing I personally have a problem with, this is about someone in the past, it is about people who are too eager and don't realize the person they are helping needs to set the limits and indicate they need help. You know like a little Boy Scout taking them across the road when they were actually going to go in the other direction.”

For the participants, help should be provided if it is asked for but, otherwise, the participants should be moving in the ways that they choose. This is not to suggest that assistance or attention shouldn't be withheld. Stevie explained: “And they [the instructors] wouldn't leave you alone. And they should not, because you're learning how to be where everybody can put their leg up.” Later Stevie mentions that the instructors: “are very approachable; they're always saying don't do, you know don't do something if it starts to hurt. Or, if you need to sit down

please feel free to sit down, and of course all of us in that group have had times when we just have to sit down or else we were going to fall over. They're very quick to recognize that."The staff are still there to provide assistance if needed, but it is not in a controlling manner that makes the participants feel dependent on others. Pip offers an example of when she did need assistance:

Pip: Yeah I can control my body when I'm sitting down.

Researcher: When sitting, but the challenge comes when you stand?

Pip: (Nods) But sometimes somebody like [the dance teacher] is there.

Researcher: And that's really important to you that you have somebody there?

Pip: Yeah, I get scared.

Not providing full choice does not conflict with autonomy if the individuals maintain an adequate range of choices that they find important to them and that help sustain their sense of worth(Quill & Brody, 1996). In Pip's case, she was offered assistance to make her experience safe and possible, the choice whether she wanted to take this offer was hers.

The DwP classes are structured in a manner that provide a fun, safe environment for the participants to engage in, while avoiding rigid protocols that could diminish one's ability to feel freedom in the movement they are executing. Accordingly, participants have an autonomous experience in the DwP sessions, which makes them satisfied and enjoy their time dancing and being physically active with the program.

Engagement: Experiencing Flow through Challenges and Mastery

Another significant QP theme observed through the experiences shared by the participants was engagement. Engagement in the QP model is defined as the feeling of being focused, motivated, and experiencing flow (Martin Ginis et al., 2016). In this study, the participants described their experiences during the DwP classes as fun and positive, while simultaneously expressing the fact that their concentration was solely on the dancing. Stevie said: “I had gone in June to experience DwP and really enjoyed it. I didn’t realize it would be so much fun. And often I’m surprised that the time is gone, and you could have thought that maybe we’ve been there 15 minutes, but our full hour is filled.” Likewise, Ramona said: “I have a hard time just standing without doing something, and I’m never bored in this class.” Both Stevie’s and Ramona’s comments demonstrate how the DwP classes have them immersed in the present moment, a key feature of the concept of flow, with flow being the complete absorption in what one does (Nakamura & Csikszentmihalyi, 2014).

Experiencing flow is a part of engagement that means to be fully immersed in an activity, where you feel involved and get enjoyment from this focus (Martin Ginis et al., 2016). When asked what exactly the DwP participants focus on during the classes, all referred to the dance exercises. Bridget, for instance, stated that one has to concentrate in class because all she thinks about is “getting it right.” Elvira responds similarly: “I think I’m just busy trying to do what she is showing us to do.” According to the participants, in the one-hour session, their full attention is on the tasks at hand and can be brought back to the tasks at hand, while other things, including PD, recede in terms of attention. This was most notable when Ramona explained those occasions when her full attention was not absorbed in the dance: “Sometimes something is off, the meds are off, somehow nothing is working, but then I don’t feel like, just feel like I am not doing my best

then.” When the mind does wander away from the class, the participants are aware and consciously make an effort to remain engaged as much as they can. Leonard described the same, where he is aware that pain sometimes makes him lose focus, saying: “Well my mind wanders sometimes, but then I come back.”

In the QP model, the themes of challenge, mastery and engagement are presented as separate elements that make up a quality participation experience. However, in this study, the themes appeared to have interacted with one another, with engagement being the experience produced by challenge and mastery. More specifically, the participants vindicated that the challenges provided for them create a desire to focus in class, and by accomplishing these challenges they become motivated to pay attention during the DwP sessions, hoping to accomplish more. This finding supports one view of engagement presented in Csikszentmihalyi’s (2000) investigation that explains two conditions leading to full engagement in an activity. These conditions include a sense that one is challenged appropriately based on one’s capacities and having clear proximal goals and immediate feedback when progress is made. Both of these conditions then create the ability for one to be focused and motivated to do an activity (Nakamura & Csikszentmihalyi, 2014). In this study, being appropriately challenged and mastering goals led to the feeling of being engaged, which the participants found to make the program enjoyable.

In order to go into more detail about the two conditions that enable the experience of flow, the way participants described feelings of challenge and mastery will be discussed. The appropriately challenging activities facilitated the participants’ desire to engage in class activities. On one hand the exercises were not so easy that participants are bored, but on the other, they were not so hard making them incapable of performing them. Bridget described the

DwP exercises as “a challenge that’s doable. It helps your body feel organized and to improve coordination.” Stevie explains the exercises in the same way: “I find each of the activities incorporated in the class are useful and I can do most of them, and I think I would feel really not positive if I sat there, finding all of it pretty difficult and I’m not, and so I think that’s good.” Leonard explains he is in the DwP program because he liked this very aspect of it, describing his ideal program as: “I just want to do something that’s not too difficult. But difficult enough so I have to focus on it.” The participant’s would often describe the DwP exercises as having a complexity that leads them to need to focus while they are in class. Elvira explains “it is very hard when they use the left leg and right hand at the same time. You got to think. That’s what you have to do in Parkinson, you should be making the brain think differently.” Bridget describes the DwP exercises: “Probably not complex if you haven’t got two left feet, but it’s fairly complex and I think it’s good, it pushes us.” The participants mention this idea of the exercises implementing coordination between the body and mind, a challenge for the participants that leads them to want to focus on the instructions given in class, in order to get exercises right, something they show desire to do.

Participants did mention certain exercises being too challenging; however, these challenges were countered with positive feelings that the participants felt after class, reflecting that the challenge was still appropriate as it provided them with a potential goal to work on. The best example of this was made by Leonard, who said: “I can do most of them in terms of skill, most of the activities. Some of them are a bit too challenging. But, I mean, I know I go home with a good feeling after the Wednesday class.” Even with the difficulty of some exercises acknowledged, the participant explained that he still feels positive after class, suggesting that the challenge experienced was constructive.

Another aspect of the DwP participants' experience of flow is the accomplished goals participants had experienced. Improvements in their dance technique or in their physiological symptoms were motivating factors for participants to want to continue engaging during class. Bridget shared some of her goals she has for herself: "I want to get everything right and improve my coordination." She later explains how good it feels when she does get the dance steps right or does "manage" to learn the dance moves in class. Bridget illustrates how the goals and improvements act as a motivating factor for her to continue participation in the DwP classes. Leonard had been attending DwP classes for ten years and noted that he always tried his best to be engaged in the activities because, for him, seeing results and feeling better after these classes contribute to his focused behaviour during the sessions. Leonard says: "Well, I think I've been holding fairly stable with my symptoms. I am benefiting from these various activities I'm participating in, as I haven't found my balance has been a concern now, but otherwise it think it is very stable, so must be doing something right". Others shared this view; for instance, Stevie, when asked to explain her decision to participate in DwP, described: "It's funny to say it because toward the end when we stand behind the chairs, I enjoy seeing how far I can bend and my operated knees are much better than it was. It doesn't hurt anymore, so it's fun to see how I can do the, you know, the ballet positions right." George's favourite part of class is the free dancing, because he can feel the level of control he has over his body, explaining: "I guess the free dancing at the end when we have to move our chairs behind. I can get a sense of how I'm doing that day, by my balance, so on and so forth." For George, mastering his control over his movements keeps him motivated to continue classes. He and other participants demonstrate how motivation to be attentive to only the dancing in class comes from these accomplishments and improvements felt by the participants. Wanting to feel they have mastered a goal again, the

participants become more attentive during class, distracted from problems outside of the class, even for a short time.

The findings of this study demonstrate that engagement is an important factor in providing a quality physical activity experience for those with PD. They are supported by previous research that demonstrated that the engagement aspect for those with PD is an essential part of participants' enjoyment of physical activity and motivation to return to class (Foster, Golden, Duncan, & Earhart, 2013). From this study, experiencing flow in the DwP classes is something that provides the participants with a quality physical activity experience. Furthermore, being challenged and feeling mastery are not separate themes in the case of this study, but rather work together to motivate a participant to experience flow. The study participants found it beneficial to be fully focused on their movements; as Pip noted at the end of her interview: "I would highly recommend it because it keeps you busy, it keeps your muscles moving."

Belongingness: Valued Relationships with Instructors

The third QP model theme that was foregrounded in this study was the participants' feeling of belongingness. The QP model defines belongingness as the building of relationships that make one feel accepted and respected on an interpersonal or social level and identifies it as an experience leading to quality participation (Martin Ginis et al., 2016). In Chapter Four it was mentioned that the social environment supported participation in the DwP through the instructors and other members. This evidence relates to, but is different from what will be presented in this section, considering that the belongingness felt by participants was strongly related to relationships that the participants themselves found significantly affected the quality of their participation experience. As will be explored below, interestingly, unlike other studies on

disability and physical activity, the relationships that were most important for the participants in this study were the ones built with the instructors, not necessarily with other participants (Foster, Golden, Duncan, & Earhart, 2013; Shirazipour, 2017). This was most pronounced when participants shared their least favourite exercise, mirroring.

The Valued Relationship between Participants and Their Instructors

Participants in this study considered their relationships with instructors to be the most significant in making their visits to the DwP program satisfying and enjoyable. Through the anecdotes that were shared by the participants in the interviews, it was evident that feelings of acceptance and respect were acquired through the relationships they have built with their instructors. One example of such a memory was provided by Leonard. After being asked why he has been coming back to class for ten years, Leonard described his first day with the DwP program: “I was not there for the first week, but I got there the second week, and I remember [the instructor] met me and came and said, ‘Hi, I am [name of instructor], may I take your boots?’ This was March, it was snowy out, and so it broke the ice. I enjoyed the session and kept coming back.” Leonard’s first day and the reason he returned is associated with this particular moment. He was welcomed by the instructor and made to feel comfortable by her attentiveness to him and this, in turn, opened an opportunity for him to build a connection with the instructor over the years. As also noted throughout Chapter Four, the connection that the participants felt with their instructors was a common theme and an important part of this connection was that not one participant felt like a stranger to the instructor. The relationship is reminiscent of the idea of ‘humans among humans’ rather than humans among disabled (Lee & Robbins, 1995), a way of

saying the participants never associated their relationship with the instructor as therapist and patient, but rather as teacher and student, or friend and friend.

A common theme that emerged out of the conversations directed at the DwP instructors was the instructors' use of praises that made participants sense positive energy; phrases such as "good job" or "that's much better." This feedback imparted feelings of significance and ability to the participants which, in turn, made them worthy and able. Bridget explains that the instructors' use of positive language is important to her: "They're always saying that we did a good job, and call us by names saying 'That was great, that was good, that's beautiful, you know. There's a lot of positive feedback, the whole class gets a good cheer so that's good.'" The instructors' use of supportive language around the focus of strengths, ability, and assets supports Gilson and Depoy's findings (2000) that language plays a role in the identification of members to a group. If derogatory words are used towards people with disabilities then they will feel like they do not belong, whereas positive words applied will represent an opening into becoming a member. In order for a participant to feel like they belong to a group, they must be reassured of their skills making it possible for them to feel their presence in the class matters (Lee & Robbins, 1995). With the instructors providing this positive energy and commentary, the participants are able to feel like they are a part of a group where their actions matter.

The notion that the DwP instructors display care towards the participants was also a common feature of the instructors that related to feelings of belongingness, as it was something that led them to feeling respected and accepted by the instructor. When asked to explain what about the DwP instructor makes them want to come to class, Leonard responded: "She's very charismatic and actually, this is all the volunteers and teachers, all are very caring people, and you feel, the feeling is good I get when I come here." Similarly, Brenda explained that a reason

for returning to the program is the people: “I just find them particularly delightful people of all ages. They have lots of empathy. I don't know if any of them have any relatives or friends that have Parkinson's.” The instructors and staff display not only a passion for dance itself but a passion for helping people with PD. The participants see this as a significant part of the program, which affects their desire to come to class. Stevie described the importance of being caring when comparing the DwP instructors with another program's staff:

And I would say the instructors make it worthwhile because when I ended DwP, 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 instructor has her class in mind and that that's kind of conveyed in how she acts.

Here Stevie notes that she preferred the DwP instructor because she felt that their demeanor displayed that they cared about helping those who attend class, which motivated her to engage in the DwP program. By comparing the DwP instructor with the yoga instructor, the importance of the display of care that the instructors have in class was made evident, seeing as DwP was continued and the yoga was not based on Stevie's perception of the instructor's level of care.

The acknowledgement of a person's successes and failures is a reflection of respect towards those with a disability, defining respect as the acceptance for the values and differences of others. Language is a way to ensure sensitivity to the struggles of a person with a disability, which can act as a method to ensure that negative stereotypes of disability are not being sustained, but instead a valued sense of self is encouraged (Rodrigues, 2015). In this particular

study, the positive appraisals provided by the instructors serve as a reminder of the participants' assets and strengths, rather than their deficits. Positive reinforcement for those with disabilities has been demonstrated to lead to higher self-confidence (Rodrigues, 2015). Stevie says: "They do address us individually, but in a positive way, to signal 'get a leg up higher', they might just come over or just quietly could take your shoulders and make you realize that you need the shoulders back. So they're there encouraging you, even when correcting you." It is made evident that there is an importance in the use of phrases that the DwP instructors use that push participants to work hard but at the same time show the belief in their abilities to do so were supportive of their disability and determination. This acceptance and respect participants experience from their relationships with the DwP instructors is associated with feeling a sense of belonging to a group and seems to play a significant role in creating a quality experience for the participants (Martin Ginis et al., 2016).

The Lack of Significant Relationships with Other Members

For the study participants, the building of valuable relationships in the DwP program was very much directed towards the instructors whereas other potential relationships, such as those with other participants or other volunteers, were framed as being of little significance to contributing to their sense of a quality participation experience. 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. To me they are a bonus, because when I was diagnosed with Parkinson's my life changed. All my friends sort of drifted away and this has given me a social life, as well as the dancing and friendships." Despite the participant acknowledging the "bonus" of socializing while at DwP, the relationships with other participants are claimed to not be a factor in attendance to class. Stevie had a similar response: "Yes, minimal and I think it is in

a sense. After you go a few times you begin to sort of say hi and how are you, and is your name Georgia, that kind of thing. There's not much time really to socialize and that's fine. I would say that it is the socialization aspect as it is secondary benefit really.” Once again, it can be noted that socializing with other participants plays a role, but a secondary one, that does not appear to affect participation levels.

The connections built with the instructors are more reason to return to class than the other people in class for the participants in this study. Some even desire to spend more time with the instructors and to have one-on-one sessions. Stevie says that the instructors are more than happy to help the participants and answer any questions but “she is there for all the total group as opposed to just one. That means time to consider time with everybody. But that's what was leading me, my thought at least to, maybe I should take up private ballet class, a beginner's class.” When asked to describe the relationship with other DwP members, Bridget explained that this program is not meant for that: “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. If some people are finding, if they are more isolated home maybe they need that class.” When Elvira was asked if she has made any friendships and she replied no, she was also asked if more opportunity to socialize in the DwP class would help, to which she answered: “Not really. I'm alright because I have the other group once a month. There I socialize with these people.” Despite being surrounded by others with similar disabilities, which opens opportunities for the participants to connect and bond with one another, the relationships with other members in class do not seem to impact the desire to participate in the program.

The interviews revealed a contradicting finding in that participants reported lacking significant relationships with their peers but still perceived value in participating among members with similar conditions, as mentioned in Chapter Four. A potential reason for this contradiction could be that the structure of the class did not enable cohesion between the DwP members, thereby making it difficult for significant relationships to form. Norcross (2010) presents group cohesion as a significant part of group therapy, improving a participant's stress levels and motivation during the sessions. He explains that the *quality* of group relationships is higher when there is a positive bond made by both the member and their leaders *and* other members, which can be achieved through positive tasks and shared group goals. A way to ensure cohesion in a group is for the leader to emphasize member interactions and present goals that the group can work on together. In the case of DwP the instructor, as in most ballet classes, simply demonstrates the exercises to the group and everyone works individually to complete the exercise. In general, there is very little opportunity for interaction to occur between members during the DwP sessions. Perhaps if the DwP leaders made effort to articulate a vision for the group for more collective goals and created opportunities for group dance activities, the participants would be able to build significant relationships. The DwP sessions do have one exercise that requires interaction between participants, and that is the mirroring exercise, however, this is the least liked exercise within the program. This further demonstrates the fact that the participants in this study lacked strong relationships with other members. The next section will discuss the mirroring exercise in more detail and reveal the reasons provided by the participants as to why this was the least liked exercise.

Mirroring: The Least Liked DwP Exercise

Despite the program providing a positive social environment for the participants where they feel like they built quality relationship with instructors and belong to a group that is inclusive, there was one DwP exercise that would repeatedly emerge as a negative experience for the participants in this study: mirroring. Mirroring consists of sitting across from another participant, assigning leader and follower, where the leader moves and the person across follows the movement as if they were the leader's reflection. Though all of the participants felt that there was no need to have the exercise removed from the program, it was by far and away the least liked by every single participant in the study. Some attention as to why this may be the case is warranted.

When it comes to the reason behind the mirroring exercise's lack of popularity, two potential explanations emerged. One was that participants felt inadequate during the exercise. Ramona explained:

I guess I'm afraid of not living up to expectations, because there's no leader it's just (pause)...Maybe it's my being an introvert again and thinking they would rather have somebody else as a partner because I know that I'm not good at dancing. I like dance though. I like group work, but not partnered activity.

George offered a similar viewpoint of mirroring saying: "Sometimes I do alright sometimes I don't. I guess it depends what mood I'm in. If I'm in a rotten mood, the mirroring, I don't do so well in the mirroring." Despite the instructor explaining that there is no right or wrong way of doing any of the exercises in class, the participants felt that there is a proper way of performing mirroring. What makes them dislike the exercise is if they feel like they are not performing up to standard. The standard the participants have set for themselves is unclear, but it's important to

note that when they are placed in a partnered situation rather than the group setting, these participants ultimately feel uncomfortable with their performance, whereas part of the safe atmosphere and appeal of the DwP program is not being pressured to perform in a certain way.

Some of the participants believed they were inadequate during the mirroring exercise because they felt they are not being as creative as they should be. Pip said “Well, I just run out of things to do.” and responds that it is “a very challenging exercise.” Similarly, Bridget said: “It’s something to think about, but then you have to think about what the heck am I going to do?” Again, the participant believed that there is a certain way the mirroring exercise needs to be executed, when in reality the same rules apply for the mirroring as for the other exercises in the class. This concern is possibly only arising in this exercise because of the intimate interaction with another participant where there is potential discrediting that could occur, whereas in a group setting it is less likely you are witnessed “doing something wrong” (Charmaz, 1983).

Whereas some participants felt uncomfortable with the exercise not because they felt they were not doing it right, others disliked the activity because they felt it’s too easy for them. Elvira explained the reason for mirroring being her least favourite exercise by saying: “I think is because it’s always the same. Like we’re always doing the same thing. I think it’s easier for us to just keep repeating. Yeah, yeah, like appallingly easy to do, like that snow exercise (mimics snow falling with hands), it is always the same.” When asked to explain why she thinks mirroring is still part of the program if everyone dislikes it, she suggested:

It’s like you are sitting with a person who really has a problem to that, like Layla, very nice person. She has trouble, she might fall, you know, I think this is to help her and help me understand you know that, we’re all the same, no matter what, you know, ‘pff the one who can’t speak.’ We have a few of those. And I feel so sorry I cannot understand them,

I'm deaf practically. And now that's a sign of Parkinson's, when they whisper, and she was whispering to me and I cannot understand. I made her repeat three times. Yeah, I find that kind of scares me sometimes when I have to sit and do exercise with the mirroring.

Though not stated directly, Elvira admits that partly the reason for feeling uncomfortable with the mirroring exercise is because she is across from someone who is in a higher stage of Parkinson's than she is. Finding the exercises too easily executed while facing someone having difficulty with it creates an uncomfortable situation for the participant. This was apparent in the interview itself, when asked to explain why she used the word "scared," Elvira steered the discussion away from the discomfort by stating that the mirroring exercise needs to be kept because it is part of the program. Whereas in a group setting the level of individual physical ability can be masked and is not in focus, it is difficult to ignore the level while sitting right across from someone else. Seeing someone vulnerable and feeling pity is putting the disease of Parkinson's in an unattractive light, but the realization is that other participants as well share this disease and that validates the realness of the suffering the disease causes, which then leads to discomfort and fear (Charmaz, 1983).

Despite one of the main valued conditions of the DwP program being the positive social environment, it is clear this feeling is not attained when participating in the mirroring exercise. Many studies on disability have found that feelings of acceptance and respect are gained through meeting people who share the same disability and therefore display common communication of knowledge and ideas, playing an important role in motivating individuals to return to sessions (Foster, Golden, Duncan, & Earhart, 2013; Timmons & MacDonald, 2008; Shirazipour, 2017). Foster et al., (2013) found that tango participants really enjoyed making connections with other

participants and even made effort to hang out after classes, building strong friendships over their experiences. Shirazipour (2017) found that veterans identified group cohesion as a significant aspect of their quality physical activity experiences, analogous to the quality element of belongingness. After these findings, a strategy was presented to have veterans helping other veterans by returning to events as an instructor or leader, which was shown to normalize the activity for those that may be more reluctant to participate or to acknowledge adapted physical activity as a legitimate form of physical activity (Shirazipour, Aiken & Latimer-Cheung, 2017). In the DwP, the mirroring exercise actually embodies this strategy, with participants taking on both the lead and follow roles in just one exercise. However, this is the least liked exercise for the DwP participants interviewed. So, unlike in the results in other studies where social interaction with other members is vital for quality participation, the participants of this study preferred to work on themselves, having the instructor act as the leader and having personal interaction with other members play little role in their desire to participate.

Concluding the QP themes experienced by the DwP participants

In summary, using the data provided and applying this data to the QP models themes, the elements behind the DwP participants' quality participation were explored. Autonomy was experienced through the given ability and support to choose how participants want to dance. In this study, two of the QP themes, challenge and mastery, related to the experience of engagement, with the appropriate challenge of the exercises leading participants to want to focus during class, and with the opportunity to accomplish these challenges leading participants to be motivated to continue classes. Lastly, belongingness was experienced through the significance placed on the relationships built with the instructors, which promoted feelings of acceptance and

respect. The theme of meaning, which is defined as feeling a contribution to personal or social meaningful goals, or having a responsibility to others (Martin Ginis et al., 2016), was not a significant theme present. Though the participants mention the DwP contributing to personal goals, it did not appear to play a significant role in attaining a quality physical activity experience.

Chapter 6: Conclusion

In this study, eight individual semi-structured interviews were conducted, where participants were asked to share their personal experiences with DwP, along with discussing their thoughts and feelings on quality of physical activity and dance. This study aimed to understand the experience of quality participation for individuals with PD who participate in a DMT program, drawing on the QP model (Martin Ginis et al., 2016). It focused on the lived experiences of those attending the DwP program, with the purpose of better understanding how a program using DMT offers opportunity for quality physical activity participation for individuals with PD. The specific objectives of this study were as follows:

1. To explore the quality experiences of people with PD participating in DMT in the DwP program; and
2. To better understand participants' experiences in DMT through the lens of the QP model (Martin Ginis et al., 2016).

The following research questions were used to fulfill the objectives:

1. What meanings (i.e., what they find personally significant) do individuals with PD derive from their experiences with the DwP program?

2. How does the experience of the DwP program relate to the concept of quality physical activity participation as conceptualized by the QP model (Martin Ginis et al., 2016)?

Subsequent to gathering and partially analyzing data for this study, newly developed elements were added to the QP model that resonated with information shared by the participants. This new research highlighted the need to attend to three conditions (physical environment, activity and social environment) as factors that enable and support participation in a Parasport program prior to attending to the themes associated with the QP model proper. In this study, these conditions were found to be significant in providing a clearer understanding of the experiences participants have had with the DwP. Chapter Four explored how participation in DwP was enabled due to the physical accessibility of the program, the affordability of it, the value placed on dance and music by the participants, and the social inclusiveness of the environment.

Chapter Five returned to the research questions and focused on presenting the shared experiences of the participants through the QP themes, exploring the meanings and satisfactions that led these individuals to have quality participation in DwP. The analysis made it apparent that the two research questions of this study interconnected, with participants deriving meanings that reflected the definitions of the QP themes. Based on the results, three out of the six themes were found to play significant roles in creating a quality experience for the participants, these included: autonomy, engagement and belongingness. Autonomy was evident through the participants' emphasis placed on having meaningful choice that is both supported and enabled. Engagement was mainly seen through the experience of flow described by the participants, with attention on the dancing being their priority during the classes. The themes of challenge and mastery contributed to the experience of flow, with the appropriate challenge of exercises leading to the need for focus, and the accomplishment of such challenges creating a positive

motivation to continue the focus. Lastly, feelings of belongingness were considerably demonstrated through the relationship built between the DwP instructors and the participants. Relationships with other members of the DwP did not play a significant role in participation for the participants of this study. In essence, five of the six themes related to how the DwP participants experienced quality participation, and what meanings they derived from the program. Meaning was the only theme that did not appear to play a significant role in creating a quality participation experience for the participants in this study. Though the participants point out various goals they make for themselves, these do not seem notably affect the satisfaction and enjoyment levels of the participants. Meaning rather seemed to represent an outcome from having a quality participation experience. More specifically, due to all of the factors that appeared to result in participants having a quality participation experience in the DwP, they found the program meaningful for them.

Discussing the Value of DMT for the DwP Participants

Along with highlighting valuable experiences that contributed to these participants' feelings of satisfaction and enjoyment with DwP, this study offers some general insight as to what DMT means for those going through PD and, even more broadly, insight as to what physical activity can mean for those with a physical disability. By coming to understand the meanings participants derived from the DwP program and exploring the themes presented by the QP model, the value of DMT for individuals who live with a disability can be discussed. Based on the interviews conducted, DwP offers a program where individuals with PD can be treated as members of a group, can break away from the stereotype of dependency, improve their self-awareness, and lastly, have a space in which they can have fun and pleasure.

Reeve (2006) frames disability as a form of social oppression involving not only restrictions on activities as a consequence of impairment but also as a consequence of inaccessible and unaccommodating social structures. Being excluded from participating in physical activities defines those with disabilities as different and not belonging to mainstream society (Reeve, 2006). The study participants found that the DwP offered a program where they are liberated as members of society, to do what they can and to move as they are able to. The DwP steers clear of devaluing its participants by providing an environment that provides choice, support, and inclusion. At DwP, they are not being stared at or misunderstood as something less than what they are, reflecting the philosophical goal of treating a patient like a person (Quill & Brody, 1996). More specifically, the instructors support the participants, but do not coddle them, or treat them in a way that emphasizes their disability. Participants are able to focus on enjoying the class, but still received a therapeutic physical activity. This underscores the critical need for persons with illness and/or disability to have access to an environment where one can feel welcomed and significant; without such settings individuals may begin internalizing negative values of disability.

Studies on individuals with disabilities have demonstrated that providing feelings of autonomy during physical activity significantly increases intrinsic motivation and perceived independence (Banack, Sabiston & Bloom, 2011). In DwP, participants are provided with independence within a safe physical environment that they value, making them feel comfortable to participate. This supports findings on autonomy where programs developing participants' autonomy by encouraging an active exchange of ideas, and the sharing of power between the participants and the instructor, serves to the best interest of the participant (Quill & Brody (1996). Experiences of being discredited, embarrassed, ignored, and otherwise devalued, can

contribute to the growing isolation of those with an illness or disability and to their subsequent reappraisals of a valued sense of self (Charmaz, 1983). Through this study, it can be demonstrated that approaches where the participants are enabled and supported to make meaningful choices work to provide individuals with a quality physical activity experience. Knowing the approach that best serves to optimize autonomy for those with disability is important in providing guidance for physical activity programs (Groce & Zola, 1993).

The participants in this study emphasized the significance placed on being able to work at their own pace. They shared that having support to make personal choices in class, without pressure from the instructors is vital in making the DwP an enjoyable place to go. A major issue for those with PD, or other motor-related disabilities, is that they are often stereotyped as dependent, causing a lack of confidence and motivation to participate in activities, which in turn diminishes their sense of autonomy (Groce & Zola, 1993). For those that do make the decision to participate in physical activities outside of the home, experiencing a lack of control over the timing or form of participation can be demeaning (Milner & Kelly, 2009). The DwP participants enjoyed that they are supported in their decisions of movement and are provided a space where they can act upon their agency. For those that have experienced a diminished activity level due to PD, it is vital to participate in programs where one can feel that they have choice in how they are participating in the activity. Having freedom of action to pursue these choices makes life seem less restrictive and the suffering of feeling dependent is consequently reduced (Charmaz, 1983).

Along with breaking stereotypes of dependency by providing opportunity to make choices, the DwP program provided an opportunity for the individuals to become more self-aware through engagement. According to Charmaz (1983), prior to being diagnosed with a chronic illness, one's self-image is partially derived from experiences and meaningful hobbies

that may no longer have available to them due to illness or disability. As time passes, and there is an accumulated sense of loss of meaning, the formally sustained self-image breaks, and it becomes important to develop new meanings and satisfactions in order to assure the development of a new valued sense of self (Charmaz, 1983). 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 and nothing else. The benefits of experiencing flow, having a focused concentration on an activity, include the increase of one's ability to be consciousness and self-aware. These are important skills to master in order to create a valued-sense of self, something that is often an issue for those diagnosed with a chronic illness (Charmaz, 1983; Nakamura & Csikszentmihalyi, 2014). The opportunity to increase their self-awareness is important for individuals with PD, as it opens a path for the individuals to develop a valued sense of self (Nakamura & Csikszentmihalyi, 2014). In general, therapies that provide an environment where those with disability can become deeply immersed proven to be beneficial, as it provides them with a space where they can be distracted away from symptoms and anxiety about illness (Timmons & MacDonald, 2008). In addition, it provides participants with an opportunity for the development of new meanings and values that can act to increase a valued sense of self (Charmaz, 1983).

Another way DwP presented value to those with PD is the high motivation to continue being engaged in physical activity. Many participants in this study attended the DwP program for several years, with two participants attending since the opening of the program (10 years). This exhibits the high motivation the participants have gained in remaining active through the DwP program. This finding on motivation to attend DMT classes is supported by other studies. For instance, one study that had participants attend a 12-month dance program, resulted in thirteen

out of sixteen participants choosing to continue attending the dance classes even after the study was over (Foster et al., 2013). Nakamura and Csikszentmihalyi (2014) explain that the enjoyment of an activity and the desire to return to it comes from the experiential rewards it provides, including the mastering of challenges and an increased self-understanding from the formulation of goals. This presents the idea that dance may offer a physical activity that acts as a stimulant to encourage continuing lessons in class (Timmons & MacDonald, 2008).

With all of the benefits of DwP explained, it's also important to remember the most simple of them: enjoyment. In what was one of the most powerful explanations as to why they participated in DwP, Ramona answered: "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 dance comes from "the desire to keep on living." For Ramona, DwP was the mechanism by which to choose life and living in the face of a disease that progressively makes it harder to control her own body. All of the participants in this study chose the DwP program as a valued activity to remain active, with one of the main reasons being it made them happy. Individuals with PD are faced with a complicated disorder that not only impacts motor abilities but can also have devastating effects on their psychosocial health. Negative experiences can be elevated by common factors that are associated with PD including living a constrained life, missing interaction with others, and having their new definition of self challenged by stereotypes (Miller et al., 2006; Moore & Knowles, 2006; Soundy, Stubbs & Roskell, 2014). Creating therapeutic programs that generate a positive experience is essential to ensure these individuals have the environment to be able to improve their well-being and mental health (Hole et al., 2014). The DwP program has shown to be a positive experience for the individuals in this study, and provided them with a space where they can have meaningful

choice, feel supported, and experience a growing self-awareness. All of these things make DMT a valuable addition to the lives of the participants who were interviewed in this project.

Considering the QP Model's Applicability to Investigating DwP

The nature of the model presents a great opportunity to explore the participation experiences of people with PD in the DwP program as the QP model is not only one of the few conceptualizations that exist for quality participation experiences, but it is also geared towards exploring the experiences of people with disabilities (Martin Ginis et al., 2016). In addition, the identified themes presented in the QP model provided a beneficial structure to analyze the experiences shared by the participants in this study. The QP model provided a clear structure that allowed the meanings and satisfactions presented by the participants to be organized. With the existence of a vast amount of definitions of experiences that could explain quality participation, providing definite six themes enabled a consistent approach to exploring what is an otherwise complex and multi-causal research objective.

Though the six themes served to aid the process of analysis, it also permitted certain obstacles. For instance, there was a tendency for data to overlap among themes, making it difficult at times to stay within the model's conceptualization of the different experiences that led to the attainment of quality physical activity participation. The best example of this was with the themes of challenge, mastery, and engagement, that all interconnected to a quality experience for the participants. The challenge of the exercises led to the need for focus and concentration during class, while also providing the experience of accomplishment if the challenges were complete. Mastering challenging exercises served as motivation to continue classes, in order to continue

achieving, while also providing stimulation for self-challenge. Engagement, the experience of flow, focus, and motivation occurred because the participants wanted to concentrate due to the challenge of exercises and accomplishments of these challenges. Overall, one can see how despite being defined as separate themes, they interconnect. Thus, when coding and developing themes, the distinct presentation of these experiential themes created reservations about what data belonged to which theme, as the results could not be easily categorized among the definitions provided.

In addition, with the QP themes being broad, the interpretation of them can be as well. For example, in Shirazipour et al. study (2017) veterans linked the experience of success in challenges was critical in feeling mastery and meaning, while in this study challenge caused higher engagement levels that led to a quality experience. Though in both studies participants wanted to be both mentally and physically appropriately challenged, the contribution of this desire to contributing to the engagement levels of participants was not mentioned in the Shirazipour et al. (2017) paper. This result may be due to the fact that the data differed, however, it can also be due to the interpretation of the themes. In one sense, challenge could be just seen as important on its own, and not connecting to the attention or focus displayed by a participant, on the other it can. Challenge in the QP model is simply defined as an appropriate challenge, but exactly what the participants should be feeling in order to say how this theme directly relates to a quality experience is not clear. These differing views demonstrate the complexities of creating one accurate definition of an element that leads to a quality participation experience. The broadness of these definitions on one hand enables more analysis of data that does relate to the experience of challenge, but the lack of specificity opens too many options, allowing different interpretations of the word.

Another problem with the definitions of the QP themes occurred regarding the theme of meaning. According to the QP model, meaning should represent a feeling that leads to a quality participation experience. Meaning in the QP model is defined as feeling a contribution to personal or social meaningful goals or having a responsibility to others. Though goals were mentioned by the participants, based on the interviews and the interpretation of them, meaning did not play a significant part in contributing to a quality participation experience. However, if meaning is defined as something that is of significance to someone, it can be viewed as an outcome that occurs due to the quality participation that is experienced. More specifically, the interviews demonstrate that participants find the DwP program meaningful for them due to all of the experiences mentioned previously. This just another example of how the interpretation of the themes can be quite wide due to the nature of the definitions.

A potential reason certain themes in this study did not match the QP model's conceptualization of quality participation is due to the limitations of the interview. Perhaps the semi-structured approach allowed for too much variety, and so the questions and probes asked did not reflect the categories created by the QP model to represent the experiential experiences of participants. Another potential reason is the fact that there is no question guide developed for the model and so the questions were developed by the researcher. With the definitions being broad, allowing for a variety of interpretations of them, there is more opportunity for researchers to develop different questions despite looking at the same model. Nevertheless, the broadness of the definitions enabled a wider search for what meanings, satisfactions, and experiences the participants shared. More strict and confining definitions of themes could have potentially led to a less in-depth data gathering and analysis. And with quality experience being a subjective and

complicated area to explore, more room for interpretation in a model enables for a more broad and rich analysis.

The QP model was helpful in providing a structure to explore the experiences of DwP participants. The model encapsulated the multidimensionality and subjective nature of participation, making it a great tool to organize the data uncovered. In addition, during the process of this research new developments for this model were created that aid to further understand the concept of quality participation. This demonstrates that the model has great potential to be applied and researched further. However, the broadness of the definitions and the interconnectedness between the themes were evident, which opens doors to different interpretations of results by researchers. Overall, to accomplish creating optimal physical activity settings for those with disabilities it is important to understand their experiences. If the themes can be interpreted in too many ways it can become difficult for researchers to agree on results and therefore implement effective strategies. In general, the QP model needs to be researched further, including more alternative forms of physical exercise, aiding to further develop the model, with more defined themes or clearer instructions in categorizing data into these themes.

Future Research Directions

The sample in this study consisted of eight individuals who attended four of the fourteen DwP locations available in the GTA area in Ontario. The nature of this small case study allowed for an in-depth analysis and understanding of participant experiences with DwP. Nonetheless, the results of this study cannot be used to make generalizations about other programs applying DMT, or to other physical activity programs for those with PD. For that reason, further research should include participants who represent a larger, more diverse group, providing a greater

understanding of the realities that impact the participation experiences of people with disability in DMT programs. Another factor that should be considered in future studies is the status of attendance. In this study, only current members of the DwP program were interviewed, similar to past studies using the QP model (Shirazipour, 2017). By considering the experiences of participants who have dropped out of DMT programs, a more comprehensive understanding physical activity experiences for individuals with disabilities can be generated.

An interesting finding of this project was that the participants considered the relationships with their instructors to be very influential in providing them with a quality participation experience, while the bonds built with other participants were considered not nearly as significant. This is different from other studies that looked at disability and physical activity, where the findings demonstrate a considerable amount of importance place on the building of relationships with other members in a program in order to have an enjoyable experience (Foster et al., 2013; Shirazipour, 2017). After examining this finding, other questions began to emerge: What makes the bond with the instructor more important than the bond with other participants who have PD? Does the relationship with the instructor offer something that a relationship with another participant does not, and if so what is it? Is the lack of friendships between participants a negative thing? Does the emphasis placed on experiencing flow relate to the dislike of the mirroring exercise? Other studies have found that social belongingness is not always needed in physical activity settings. For instance, Paralympic athletes did not feel the need to be connected to others in their social environment to be intrinsically motivated toward their elite sport (Banack, Sabiston & Bloom, 2011). The motivation for these athletes resulted from coaches that supported their psychological needs, allowing them to not depend on feeling belongingness to other members in their sport (Banack, Sabiston & Bloom, 2011). This finding on Paralympic

athletes may connect to the DwP participants, where a strong relationship with the instructors leaves them not requiring any deep or meaningful relationships with other group members. It is also possible that other DwP members, who were not interviewed for this study, feel differently about the instructor and the mirroring exercise. Nonetheless, with participants in this study presenting results that demonstrate relationships with instructors are more significant than relationships with other members, future studies can try to understand more clearly why this was the case and how it may affect the structure of programs created for those with PD. In addition, future studies should include interviews with the instructors and/or volunteers, inferring about their relationships with the participants by asking open ended questions. This would aid in understanding the relationship between the participants and instructor in more depth and from both sides, offering more insight onto this finding.

The intent of this study was to create a greater understanding of the experiences of quality participation for individuals with PD who participate in the DwP program, drawing on the QP model (Martin Ginis et al., 2016). It focused on the lived experiences of those attending the DwP program, with the purpose of better understanding how a program using DMT offers opportunity for quality physical activity participation for individuals with PD. Through this project knowledge was gained in what enables and supports quality participation in the DwP program, as well as, what aspects of quality participation are experienced by individuals in the DwP program. This research may be used to modify the DwP program, providing recommendations to other programs using DMT for PD care, and optimize participation experiences of PD participants. This study also highlights the QP models' versatility as a conceptualization of quality participation when studying differing populations and programs. It is anticipated the results of this study can be used to improve the physical activity experience of

individuals suffering from PD by highlighting dance movement as an important complementary therapy that can be incorporated into their care plans.

Though this study was small, it was a first of its kind, offering a glimpse into what participants with PD find meaningful and satisfying from the DwP program. Expanding knowledge on their experiences will add much needed information that has often been absent in existing health and dance therapy research. This research will further promote the importance of studying DMT as a physical activity available for those with disabilities and draw attention to various factors associated with quality participation. Integrating this knowledge into the existing body of research in other domains will help to create a more comprehensive view to better understand how dance movement is used as complementary and alternative healthcare with PD. In a broader sense, it is my hope for this project to contribute to the understanding of quality physical activity in the sphere of disability.

References

- Agich, G. J. (1990). Reassessing autonomy in long-term care. *Hastings Center Report*, 20(6), 12-17.
- Ahlskog, J. E. (2011). Does vigorous exercise have a neuroprotective effect in Parkinson disease?. *Neurology*, 77(3), 288-294.
- Baatile, J., Langbein, W. E., Weaver, F., Maloney, C., & Jost, M. B. (2000). Effect of exercise on perceived quality of life of individuals with Parkinson's disease. *Journal of rehabilitation research and development*, 37(5), 529.
- Banack, H. R., Sabiston, C. M., & Bloom, G. A. (2011). Coach autonomy support, basic need satisfaction, and intrinsic motivation of paralympic athletes. *Research quarterly for exercise and sport*, 82(4), 722-730.
- Baxter, P., & Jack, S. (2008). Qualitative case study methodology: Study design and implementation for novice researchers. *The qualitative report*, 13(4), 544-559.
- Charmaz, K. (1983). Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of health & illness*, 5(2), 168-195.
- Charmaz, K., & Rosenfeld, D. (2006). Reflections of the body, images of self: Visibility and invisibility in chronic illness and disability. *Body/embodiment: Symbolic interaction and the sociology of the body*, 35-50.
- Cohen, S., & McKay, G. (1984). Social support, stress and the buffering hypothesis: A theoretical analysis. *Handbook of psychology and health*, 4, 253-267.
- Crizzle, A. M., & Newhouse, I. J. (2006). Is physical exercise beneficial for persons with Parkinson's disease? *Clinical Journal of Sport Medicine*, 16(5), 422-425.
- Csikszentmihalyi, M. (2000). *Beyond boredom and anxiety*. Jossey-Bass.

Dancing with Parkinson's. (2015). Retrieved June 29, 2017, from

<http://www.dancingwithparkinsons.com/>

de Dreu, M. J., Van Der Wilk, A. S. D., Poppe, E., Kwakkel, G., & van Wegen, E. E. (2012).

Rehabilitation, exercise therapy and music in patients with Parkinson's disease: a meta analysis of the effects of music-based movement therapy on walking ability, balance and quality of life. *Parkinsonism & related disorders*, 18, S114-S119.

DeSouza, J. (2017) "Twelve-Week Dance Class Helps Those with Parkinson's Disease." *YFile*

York University's News, 5 Oct. 2017, yfile.news.yorku.ca/2017/10/05/twelve-week-dance-class-helps-those-with-parkinsons-disease/.

Duncan, R. P., & Earhart, G. M. (2012). Randomized controlled trial of community-based

dancing to modify disease progression in Parkinson disease. *Neurorehabilitation and neural repair*, 26(2), 132-143.

Evans, M. B., Shirazipour, C. H., Allan, V., Zanhour, M., Sweet, S. N., Ginis, K. A. M., &

Latimer-Cheung, A. E. (2018). Integrating insights from the parasport community to understand optimal Experiences: The Quality Parasport Participation Framework. *Psychology of Sport and Exercise*.

Galletta, A. (2013). *Mastering the semi-structured interview and beyond: From research design to analysis and publication*. NYU Press.

GhorbaniSaeedian, R., Nagyova, I., Krokavcova, M., Skorvanek, M., Rosenberger, J.,

Gdovinova, Z., & van Dijk, J. P. (2014). The role of social support in anxiety and depression among Parkinson's disease patients. *Disability and rehabilitation*, 36(24), 2044-2049.

Gilson, S. F., & Depoy, E. (2000). Multiculturalism and disability: A critical perspective.

Disability & Society, 15(2), 207-218.

- Goodwin, V. A., Richards, S. H., Taylor, R. S., Taylor, A. H., & Campbell, J. L. (2008). The effectiveness of exercise interventions for people with Parkinson's disease: A systematic review and meta-analysis. *Movement disorders*, 23(5), 631-640.
- Guillemin, M., & Gillam, L. (2004). Ethics, reflexivity, and “ethically important moments” in research. *Qualitative inquiry*, 10(2), 261-280.
- Fahn, S. (2003). Description of Parkinson's disease as a clinical syndrome. *Annals of the New York Academy of Sciences*, 991(1), 1-14.
- Fereday, J., & Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International journal of qualitative methods*, 5(1), 80-92.
- Foster, E. R., Golden, L., Duncan, R. P., & Earhart, G. M. (2013). Community-based Argentine tango dance program is associated with increased activity participation among individuals with Parkinson's disease. *Archives of physical medicine and rehabilitation*, 94(2), 240-249.
- Hackney, M. E., & Bennett, C. G. (2014). Dance therapy for individuals with Parkinson's disease: improving quality of life. *Journal of Parkinsonism and Restless Legs Syndrome*, 4, 17-25.
- Hanna, J. L. (1995). The power of dance: Health and healing. *The Journal of Alternative and Complementary Medicine*, 1(4), 323-331.
- Hermanowicz, J. C. (2002). The great interview: 25 strategies for studying people in bed. *Qualitative sociology*, 25(4), 479-499.
- Hirsch, M. A., & Farley, B. G. (2009). Exercise and neuroplasticity in persons living with Parkinson's disease. *European Journal of Physical and Rehabilitation Medicine*.

- Hole, E., Stubbs, B., Roskell, C., & Soundy, A. (2014). The patient's experience of the psychosocial process that influences identity following stroke rehabilitation: a metaethnography. *The Scientific World Journal*, 2014.
- Houston, S., & McGill, A. (2013). A mixed-methods study into ballet for people living with Parkinson's. *Arts & health*, 5(2), 103-119.
- Kelly, M. P., & Field, D. (1996). Medical sociology, chronic illness and the body. *Sociology of Health & Illness*, 18(2), 241-257.
- Lee, R. M., & Robbins, S. B. (1995). Measuring belongingness: The social connectedness and the social assurance scales. *Journal of counseling psychology*, 42(2), 232.
- Livneh, H., & Antonak, R. F. (2005). Psychosocial adaptation to chronic illness and disability: A primer for counselors. *Journal of Counseling & Development*, 83(1), 12-20.
- Marshall, M. N. (1996). Sampling for qualitative research. *Family practice*, 13(6), 522-526.
- Martin Ginis, K. A. M., Evans, M. B., Mortenson, W. B., & Noreau, L. (2016). Broadening the conceptualization of participation of persons with physical disabilities: a configurative review and recommendations. *Archives of physical medicine and rehabilitation*, 98(2), 395-402.
- Martin Ginis, K. A. (2016, April 05). We need data on physical activity among people with disabilities. Retrieved June 21, 2017, from <https://www.thespec.com/opinion/story/6439585-we-need-data-on-physical-activity-among-people-with-disabilities/>
- Martin Ginis, K. A., & Hicks, A. L. (2007). Considerations for the development of a physical activity guide for Canadians with physical disabilities. *Applied Physiology, Nutrition, and Metabolism*, 32(S2E), S135-S147.

- McMillan, D. W. (1996). Sense of community. *Journal of community psychology*, 24(4), 315-325.
- Milner, P., & Kelly, B. (2009). Community participation and inclusion: People with disabilities defining their place. *Disability & Society*, 24(1), 47-62.
- Moore, S., & Knowles, S. (2007). Beliefs and knowledge about Parkinson's disease. *Sensoria: A Journal of Mind, Brain & Culture*, 2(1), 15-21.
- Nakamura, J., & Csikszentmihalyi, M. (2014). The concept of flow. In *Flow and the foundations of positive psychology* (pp. 239-263). Springer Netherlands.
- Norcross, J. C., & Wampold, B. E. (2011). Evidence-based therapy relationships: Research conclusions and clinical practices. *Psychotherapy*, 48(1), 98.
- Parkinson Canada. (2017) Retrieved June 16, 2017, from http://www.parkinson.ca/site/c.kgLNIWODKpF/b.3531701/k.86FE/Parkinson_Canada.m
- Poewe, W. (2008). Non-motor symptoms in Parkinson's disease. *European Journal of Neurology*, 15(s1), 14-20.
- Polkinghorne, D. E. (2005). Language and meaning: Data collection in qualitative research. *Journal of counseling psychology*, 52(2), 137.
- Putnam, M., Geenen, S., Powers, L., & Saxton, M. (2003). Health and wellness: People with disabilities discuss barriers and facilitators to well being. *Journal of Rehabilitation*, 69(1), 37.
- Roger, K. S., & Medved, M. (2010). Living with Parkinson's disease—managing identity together. *International Journal of Qualitative Studies on Health and Well-being*, 5(2), 5129.

- Reeve, D. (2006). Towards a psychology of disability: The emotional effects of living in a disabling society. *Disability and psychology: Critical introductions and reflections*, 94-107.
- Rodrigues, J. M. (2015). Spoken Language to be Embraced and Avoided Around Disability: Words That Impact Identity and Sense of Achievement.
- Rosenberg, D. E., Bombardier, C. H., Hoffman, J. M., & Belza, B. (2011). Physical activity among persons aging with mobility disabilities: shaping a research agenda. *Journal of aging research*, 2011.
- Schmidt, C. (2004). The analysis of semi-structured interviews. *A companion to qualitative research*, 253-258.
- Sharp, K., & Hewitt, J. (2014). Dance as an intervention for people with Parkinson's disease: a systematic review and meta-analysis. *Neuroscience & Biobehavioral Reviews*, 47, 445-456.
- Shirazipour, C. H. (2016). *Quality Physical Activity Participation for Military Veterans with a Physical Disability* (Doctoral dissertation, Queen's University).
- Shirazipour, C. H., Aiken, A. B., & Latimer-Cheung, A. E. (2017). Exploring strategies used to deliver physical activity experiences to Veterans with a physical disability. *Disability and rehabilitation*, 1-8.
- Shirazipour, C. H., Evans, M. B., Caddick, N., Smith, B., Aiken, A. B., Ginis, K. A. M., & Latimer-Cheung, A. E. (2017). Quality participation experiences in the physical activity domain: Perspectives of veterans with a physical disability. *Psychology of Sport and Exercise*, 29, 40-50.

- Soundy, A., Stubbs, B., & Roskell, C. (2014). The experience of Parkinson's disease: a systematic review and meta-ethnography. *The Scientific World Journal*, 2014.
- Strassel, J. K., Cherkin, D. C., Steuten, L., Sherman, K. J., & Vrijhoef, H. J. (2011). A systematic review of the evidence for the effectiveness of dance therapy. *Alternative therapies in health and medicine*, 17(3), 50.
- Timmons, A., & MacDonald, E. (2008). 'Alchemy and Magic': the experience of using clay for people with chronic illness and disability. *British Journal of Occupational Therapy*, 71(3), 86-94.
- Trost, S. G., Owen, N., Bauman, A. E., Sallis, J. F., & Brown, W. (2002). Correlates of adults' participation in physical activity: review and update. *Medicine & Science in Sports & Exercise*, 34(12), 1996-2001.
- Warburton, D. E., Nicol, C. W., & Bredin, S. S. (2006). Health benefits of physical activity: the evidence. *Canadian medical association journal*, 174(6), 801-809.
- Warren, C. A., & Williams, K. N. (2008). Interviewing elderly residents in assisted living. *Qualitative Sociology*, 31(4), 407.
- World Health Organization. (2017, October 05). Disabilities. Retrieved June 12, 2018, from <http://www.who.int/topics/disabilities/en/>
- Yin, R. K. (2003). Case study research (Vol. 5). *Thousand Oaks, California*.
- Yin, R. K. (2013). *Case study research: Design and methods*. Sage publications.

Appendix A: Study Information Sheet

Title: Exploring Dance Movement Therapy as Quality Physical Activity for People with Parkinson's Disease

Principal Investigator: Elizabeth Kalashnikova, MSc Candidate (York University)

Supervisor: Rebecca Bassett-Gunter, PhD and Parissa Safai, PhD (York University)

To Whom It May Concern,

I am conducting research on the quality of physical activity experiences of people with Parkinson's Disease (PD) while they are participating in the Dancing with Parkinson's program. The objectives of this research are: 1) to explore the quality experiences of individuals with PD participating in Dancing with Parkinson's, including the role dance plays in their lives; and 2) to better understand how dance movement therapy impacts participants' sense of quality physical activity participation.

I am hoping to recruit participants for in-depth, one-on-one interviews that will last between 30 to 90 minutes. The interviews will focus on your experiences with quality physical activity and dance movement therapy. Your participation in study would be invaluable.

The interview will be audiotaped and transcribed. You can stop the interview at any point in time or decline to answer any specific question. All interview materials (e.g., notes, tapes and transcripts) will be kept in a secure, locked cabinet. All information collected will be kept **strictly confidential**. You can review your transcript at any point in time during the study. Any material used in publications resulting from this study will have identifying characteristics or statements omitted or paraphrased to protect your identity. There is no financial compensation to those participating in the study.

The study has minimal risks and the decision to participate or not is **completely voluntary**. This study offers you the opportunity to share your experiences of quality physical activity, which will contribute to expanding our knowledge on this topic in the socio-cultural study of physical activity and health.

For more information, please contact Elizabeth Kalashnikova. Thank you in advance for your consideration.

Sincerely,

Elizabeth Kalashnikova, MSc Candidate

Appendix B

Informed Consent Form

Date:

Project Title: Exploring Dance Movement Therapy as Quality Physical Activity for People with Parkinson's Disease

Investigator: Elizabeth Kalashnikova, BSc (York University)

Supervisor: Rebecca Bassett-Gunter, PhD and Parissa Safai, PhD (York University)

This Informed Consent Form, in conjunction with the Study Information Sheet, should give you a basic idea of the research project and what your participation will involve. A copy of both the Informed Consent Form and Study Information Sheet will be left for your records and reference. If you have further questions or concerns, please feel free to contact Elizabeth Kalashnikova.

Purpose of the research:

The objective of this study is to investigate the physical activity experiences of people participating in the Dancing with Parkinson's program. This study is also focused on better understanding what meanings and satisfactions are gained from this program, and what constitutes quality participation for people in this dance program.

What you will be asked to do in the research:

You will be asked to participate in one (1) 30-60 minutes semi-structured interview focused on your personal experiences with Dancing with Parkinson's. In addition, you will be asked to discuss your thoughts and feelings on quality of physical activity, dance, more broadly.

Risks and discomforts:

We do not foresee any risks or discomfort from your participation in the research. Due to the nature of PD, participants will be ensured a safe and comfortable environment. Furthermore, participants will be consulted as to whether they require or would like the involvement of or assistance from their caregiver during the interview should they feel that will enhance their comfort and convenience. If such assistance is requested by the participant, arrangements will be made prior to the interview. Furthermore, if requested by the participant at any point in time in the study, contact information for support resources (e.g., Parkinson Canada) will be made available.

There is no financial compensation for research participants.

Benefits of the research and benefits to you:

You will benefit by having the opportunity to share your insight on quality physical activity experiences with the Dancing with Parkinson's program, as well as contribute to expanding our knowledge on this topic in the study of physical activity, dance and health.

Voluntary participation:

The decision to participate or not is **completely voluntary** and you may choose to stop participating at any time. Your decision not to participate will not influence the nature of your relationship with the yoga studio or York University either now, or in the future.

Withdrawal from the study:

You CAN stop participating in the study at any time, for any reason, **without consequence**. Your decision to stop participating, or to refuse to answer particular questions, will not affect your relationship with the researchers, York University, or any other group associated with this project. In the event that you withdraw from the study, all associated data collected will be immediately destroyed.

Confidentiality:

The interview will be audiotaped and transcribed, but the name of the participant will not be recorded. Any material used in publications resulting from this study will have identifying characteristics omitted or paraphrased to maintain your **anonymity**. **Confidentiality** will be provided to the fullest extent possible by law.

All interview materials and data will be kept in a locked facility accessible only to the researcher. All data (interviews and field notes) will be stored under lock-and-key until the end of December 2019 and then will be permanently destroyed.

Questions about the research?

If you have any further questions regarding the research in general or your role, as a participant, in the study you may contact the researcher, Elizabeth Kalashnikova or her supervisors; Dr. Rebecca Bassett-Gunter or Dr. Parissa Safai. Furthermore, the School of Kinesiology and Health Science Graduate Program office may also be contacted for further information.

This research has been reviewed and approved by the Human Participants Review Sub-Committee, York University's Ethics Review Board and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the study, you may contact the Senior Manager and Policy Advisor for the Office of Research Ethics, 309 York Lanes, York University.

Legal Rights and Signatures:

I, _____, consent to participate in *Exploring Dance Movement Therapy as a Quality Physical Activity for People with Parkinson's Disease* conducted by Elizabeth Kalashnikova. I have understood the nature of this project and wish to participate. I am not waiving any of my legal rights by signing this form. My signature below indicates my consent.

Signature _____
Participant

Date _____

Signature_____

Principal Investigator

Date_____

Additional consent

I give consent to the researcher, Elizabeth Kalashnikova, to use this method of data collection:

☐ Audio recording

Signature_____

Participant

Date_____

Exploring Dance Movement Therapy as Quality Physical Activity for People with Parkinson's Disease

Elizabeth Kalashnikova

Appendix C Semi-Structured Interview Guide

Opening Script:

Hi. My name is Elizabeth and I am a Masters candidate conducting research on the quality of physical activity experiences of people with Parkinson's Disease (PD) while they are participating in the Dancing with Parkinson's program. In this interview I will ask you various question so that you can discuss your thoughts and feelings on quality of physical activity, dance, more broadly. You CAN stop participating in the study at any time, for any reason, without consequence. Your decision to stop participating, or to refuse to answer particular questions, will not affect your relationship with the researchers, York University, or any other group associated with this project. Thank you in advance for this opportunity to share your insight on quality physical activity experiences with the Dancing with Parkinson's program, as well as contribute to expanding our knowledge on this topic in the study of physical activity, dance and health.

1. Tell me about yourself.

Probes: Describe your background/experiences surrounding dance and or physical activity while living with Parkinson's.

2. Describe your current involvement in the Dancing with Parkinson's program.

*Probes :*How did you first become involved with the Dancing with Parkinson's program? How often do you come for classes? How much time do you dedicate to this in total?

3. (Autonomy; to have independence, choice and control):

Describe what do you do in these classes?

Probes: Do you feel you are able to perform to the best of your abilities? Do you feel you can easily engage in the activities? What sense of control do you have in these classes? What do you feel is your level of choice in these classes?

4. (Belongingness; to feel accepted and respected):

Describe the atmosphere of these dance classes?

Probes: Would you say you feel welcomed, if yes, how so? Do you feel connected to other students, teachers or volunteers in the class, if so with whom and why? Describe the relationship you have with your instructors/volunteers/other dancers.

5. (Challenge):

What are some of the specific goals you have with the Dancing with Parkinson's program?

Probes: Does the program provide you with goals to reach? What are some of the positive and negative aspects of these classes? How does this class compare to other physical activities you may have taken part in? Does this program meet your preferences and expectations? If so how? If not, why?

6. (Engagement; motivated, focused, involved and experiencing flow);
What motivates you to participate in the DwP?

Probes: During these sessions do you feel focused/ involved? What were your expectations/impressions of the dance movement sessions at the beginning; if your impressions changed, how so? What did you think of dance as a physical activity prior to starting these classes? If you had any, what have your other physical activity experiences been like since you started these dance classes?

7. (Mastery; having a sense of accomplishment)

How do these dance classes make you feel about yourself?

Probes: Does this program inspire you in anyway, if so how? Do you receive feedback in these sessions, do you like or dislike this? What do you believe you have gained/achieved from these classes?

8. (Meaning; feeling a contribution to personal or social meaningful goals)

How does dance contribute to your personal goals?

Probes: What does dance offer you in terms of social goals? What meaning does dance give you? Do you have feelings of responsibility from these classes, to yourself or others?

9. Do you have any additional thoughts or comments you would like to share with me? Is there anything that we didn't discuss that you feel is important to this discussion? Do you have any questions for me?