

**More Than Just Dancing:
The Experiences of Individuals With Parkinson's Disease Who Participate in A
Community-based Therapeutic Dance Program**

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Group 13

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ABSTRACT

Purpose. To explore and describe the experiences of people living with Parkinson's disease (PWP) who participate in community-based therapeutic dance programs.

Methods. A qualitative descriptive design was employed using one-on-one semi-structured interviews, 30-60 minutes in length. Individuals with Parkinson's disease (PD) who participated in the dance programs at York West Active Living Centre or Trinity-St. Paul's Centre were recruited. Interviews were audio-recorded, transcribed, de-identified and then inputted into NVivo 10 software for analysis. A content analysis approach was used with an inductive analysis method to generate a coding scheme. Group discussion was conducted to allow development of overarching themes.

Results. Ten participants' responses revealed that the dance program allows for improvement of the self and regaining of one's identity through self-management of their disease. There were positive influences of socialization through the class improving quality of life and decreasing isolation. The class acts as a means of communicating through music and dance to enhance connection with others.

Conclusions. Dancing with Parkinson's classes allow for redevelopment of the social self in PWP through creating a comfortable environment for socialization, which can aid in an improved sense of enjoyment in life. Dance programs provide opportunities for social interaction, non-verbal communication and self-improvement, re-establishing self-identity and a sense of usefulness. This study provides unique insight into the experience of participating in a dance program from the perspective of individuals with PD.

Key Words. Parkinson's disease, dance, qualitative research, identity, social interaction

INTRODUCTION

Parkinson's disease (PD) is a progressive neurodegenerative disorder currently affecting nearly 100 000 Canadians.¹ PD is characterized by postural tremor, rigidity, akinesia and postural instability, as well as a "freezing" phenomenon that occurs when passing through thresholds such as doorways.² These symptoms hinder the ability to perform voluntary movement, profoundly affecting gait and functional capacity.^{2,3} Non-motor signs and symptoms such as fatigue, cognitive changes and mood disorders accompany impairments in functional mobility.¹

Encompassed within the non-motor signs and symptoms are the psychosocial aspects that accompany chronic disease such as social isolation, decreased self-efficacy, depression, and having an individual's identity become defined by disease.^{4,5} These elements all impact health-related quality of life (QOL); thus, findings show that people with Parkinson's disease (PWP) rate their health-related QOL lower than controls.⁶⁻⁸ It is therefore important to focus on both motor and psychosocial aspects of PD when forming a management plan.

First line management of PD includes pharmacological agents; however, they do not modify disease progression as they are not neuroprotective.⁹ It is therefore essential to consider exercise and physical therapy (PT) as adjunctive interventions for comprehensive PD management. Physical therapy includes exercise programs to improve balance and physical capacity, as well as cognitive movement strategies for transfers and gait.^{10,11}

Group-based dance programs have recently emerged from the literature as management strategies for PD, and appear to be promising adjunctive therapies as they address the social, emotional and physical aspects of living with a chronic disease. Much of the research to date has evaluated changes in motor impairments through dance.^{3,12,13} Literature focuses on changes in balance, gait, and endurance before and after dance program participation, as assessed by various outcome measures.¹²⁻¹⁵ The aforementioned studies support the notion that dance and music positively affect movement initiation, gait speed and multitasking through a variety of speculated neurological mechanisms.^{11,12,16-18}

Individuals with Parkinson's report decreased participation in a variety of life situations commonly due to the unpredictable nature of the disease, psychological changes, and phobia around socialization.¹⁹⁻²¹ Dance plays a role in enhancing participation in aspects of daily living, which is important because of its protective effect on physical and cognitive decline, as well as its correlation with increased QOL.^{13,22} Foster et al. found that participation in leisure and social activities significantly increased in PWP who enrolled in a 12-month tango dance program; however, they did not directly ask participants which aspects they felt were most beneficial in improving participation.²² Thus, the biopsychosocial contributors that led to increased participation remain unclear.

In addition, participants reported decreased feelings of fatigue, anxiety, and anger; however the research does not explain why.^{12,23} These findings could be due to the notion that dance allows PWP to re-define their identity so that it revolves less around their diagnosis.²⁴ For example, PWP often experience loss of facial expression, and dance offers an opportunity to

increase self-expression through movement and imagery. Furthermore, the enjoyable social nature of dance and the opportunity for social engagement could contribute to improved mood.¹⁶ One can speculate on the factors contributing to these findings, but to date the exact mechanism remains unclear.

While dance programs for PWP appear to have positive effects on mobility, social interaction and participation in daily activities, most of these findings are drawn from quantitative studies using before-and-after designs with small sample sizes. To our knowledge, there has only been one study conducted that addresses participants' subjective experiences in these dance programs. Westheimer asked four open-ended questions via e-mail in addition to a QOL scale to determine participants' perceptions about a dance program for PWP.²⁴ While participants' e-mail responses provided more insight than the QOL scale, a more in-depth study approach is required to further understand the participants' perspectives on how dance impacts all aspects of their lives and to explore the reasons behind physical and psychosocial changes.^{12,24,25}

There continues to be a gap in our understanding of the individuals' perceptions regarding their goals, experiences and views on dance programs for PWP. This qualitative study will provide insight into how participants perceive the community-based dance program they attend, as well as if the physical and psychosocial changes measured in previous literature are consistent with the participants' perceptions.

METHODS

Study Design. The study was a qualitative descriptive design that used semi-structured interviews to encourage participants to share their perspectives of the program, and for in-depth exploration of experiences and perceptions not afforded through other methods such as surveys.

Participants. A convenience sample of individuals living with PD who participated in the dance programs at York West Active Living Centre (YWALC) or Trinity-St. Paul's Centre (TSP) were recruited. The YWALC is a not-for-profit older adult community centre located in the Northwestern Toronto area. The TSP is a fully accessible community centre that serves a diverse downtown Toronto neighbourhood. Participants met the following inclusion criteria: (i) identified as living with PD; (ii) participated in the weekly "Dancing with Parkinson's" (DWP) class; (iii) able to speak and understand English or had a translator such as a family member; (iv) able and willing to participate in a 60 minute one-on-one, semi-structured interview; and (v) able to provide informed consent.

Description of Dance Class. The one hour-long DWP classes are held weekly at each centre and are taught in a group format by professional dancers. There is a different instructor at each location; however, the instructor at YWALC was trained in DWP by the instructor who teaches at TSP and uses the same dance components. Dance activities during the class include seated movements of the arms and legs, tapping the feet, story-telling through music and dance, standing sequences, and partnered activities (mirroring) where one participant leads and the other follows. The class at YWALC is a new program, held in an exercise room at the centre with glass windows that open out to the hallway; there is a small group of participants (4) and one

volunteer to assist participants where necessary. At TSP, the class is well established and takes place in a large dance studio, which accommodates the 15-20 participants, and there are several volunteers available to assist, as well as a pianist who provides musical accompaniment. It is important to note that the DWP program at TSP is a larger class in a larger space; there is a fee required, and it is a stand-alone class. The YWALC program is held at a community centre offering a spectrum of activities and services in addition to DWP, and a minimal fee is required.

Data Collection. Data were collected through face-to-face interviews using a semi-structured interview guide and structured demographic questions. Questions for the interview guide were derived from the study objectives and informed by previous literature. The researchers reviewed the questions with input from faculty members and research advisors, and minor revisions to the interview guide were made following initial reading of the first transcript. Interviews were 30-60 minutes in length and were conducted in a private space at the centre or in participants' homes by 1-2 researchers (one interviewer and one observer). Interviews were audio recorded, transcribed and de-identified, and then imported into NVivo 10 software application for analysis.

Data Analysis. Data analysis was conducted using a content analysis approach, informed by the methods of Hsieh and Shannon, and Braun and Clarke.^{26,27} Using an inductive and thematic analysis method allowed new insights to emerge from the data itself and ensured that initial codes and eventual themes were derived directly from the participants' responses.²⁸ All five researchers completed an initial reading of the first transcript, then discussed early impressions and ideas, and generated preliminary codes.^{27,28} For each transcript, two researchers individually performed a detailed line-by-line coding process and then met to identify keywords and concepts.^{26,28,29} All researchers then met to identify patterns and generate an initial thematic map, defining categories and subcategories, and the data were reviewed and re-coded using these newly defined categories.²⁶ Through group discussion and regular meetings, the categories were analyzed in order to identify recurring themes in the data. The researchers reviewed the themes in the context of the entire data set as well as in relation to the objectives of the study.²⁹ Data analysis was completed when no further substantial information was found, inconsistencies were addressed, and the researchers decided upon representative themes and concepts.²⁶ Rigour was ensured through frequent discussions among the research team, reading and reviewing the data multiple times in persistent observation, peer debriefing to discuss interpretations of the findings in order to arrive at consensus, and continual movement between data collection and analysis.^{27,28,30}

RESULTS

Participant Characteristics. Ten participants, enrolled in one of two community-based dance programs were included in the study (Table 1). Eight participants attended the class at TSP and two participated at YWALC. Many have been participating consistently 1-2 times per week at a variety of sites for up to two years.

Connecting Through Dance. The need for socialization was articulated as a central motivator for attending class as participants admitted that living with PD can be isolating. The descriptions of participants' social experiences related to DWP varied largely between individuals; responses ranged from casual "chit-chat" before and after class, to more meaningful interaction that

allowed friendships to extend beyond the program. Participants appreciated the open, comfortable environment established within the class, and partly ascribed this to feeling they had become part of a larger group that understands what each member is going through:

When you get a Parkinson's diagnosis, [you] tend to back into a cage somewhere where nobody can see my weaknesses. You tend to exclude yourself from society. When you join something like Dancing with Parkinson's you become part of a larger group and it's much easier to fight that weakness... The other classmates are a benefit that I didn't expect or think about at the time.^[P9]

Conversely, some participants reported that the class lacked opportunity for social interaction and required a more structured approach to fostering communication between participants. Nevertheless, participants reported exchanging encouragement and support with their peers.

Additionally, dancing and music were cited as tools for communicating with fellow classmates. Participants reported being able to connect with and acknowledge each other through music, thereby creating a social atmosphere without words. This was especially meaningful for interacting with participants who had difficulty with oral motor skills and/or facial expression: "...to be able to communicate with people who can't speak, or can hardly move, or whose faces are free of any emotion... you are communicating through dance, through music. And I think that's quite profound."^[P3]

Redefining the Self. Participants suggested that the DWP class helped them to regain some sense of control over their lives and the disease after reporting a tendency to lose control, both physically and emotionally, after a Parkinson's diagnosis. They also noted periods of frustration, anger, and adjustment related to giving up work, deceleration of previously busy lifestyles, and having to give up activities previously considered fundamental to independent living (e.g. driving). They struggled with the idea that deterioration is inevitable and that the future is uncertain, and one participant suggested that people living with a chronic illness struggle to find balance between actively managing the condition and feeling that they are surrendering to the role of a sick person: "People don't like to admit that they have an illness, so they think, 'well if I go to that class then I'm going to be giving in to the illness'."^[P2]

One participant reported being "in control of my body more" during the class, and others expressed that changes in perspective and attitude were necessary for moving forward and regaining control post-Parkinson's diagnosis. They had made conscious decisions to be proactive, patient and positive in their approach to managing chronic disease and identified the DWP class as an avenue to practice increased command over mindset. Another participant also alluded to a shift in thinking from an externally to internally-mediated locus of control, which emphasized the importance of appreciating and rewarding yourself for participating in the process rather than achieving an externally determined "good" outcome: "I learned through class that it's how you work in class as opposed to, is it good or is it bad. It's as good as you want to make it."^[P10] This shift in attitude may be linked to how in control they feel. As participants explained:

You get what you put in. It's really in your control.^[P10]

So much is controlled by up here [points to head]. If you get up and you're determined to have a bad day, you'll probably have a bad day.^[P8]

Many reported seeking knowledge to become proficient in self-management and participated in several activities, including DWP as part of a larger, comprehensive self-management program. The class was identified as an arena to self-modify activities, and more importantly to do something for the self: "Going to class you're not giving in – you're getting back. You're getting something to help yourself."^[P2]

Above all, DWP provided participants with opportunities for "getting involved", and to "give back to the community" and "put back into the environment what I've gained from it". Almost all participants reported volunteer involvement in community events related to PD, which enabled them to "give support and feel useful" and provided a sense of purpose. Many participants agreed that the class had a positive impact on their QOL: "It sort of gave me a purpose, you know... when I found out that it was Parkinson's I thought that I was just going downhill. And once I joined the program... you walk faster, you look better – there's a glow on your face."^[P6]

Dance and the Mind. Participants reported that the class provided an opportunity to coordinate parts of the body in new ways and promoted use of different areas of the brain. Cognitive tasks of daily life they identified as difficult included multitasking, perceptual ability, initiating tasks, planning, and follow through. One participant described a "mind fog" that set in during concentrated tasks; others disclosed similar symptoms such as "slow" memory, difficulty focusing, and losing train of thought. However, many noticed improvements in coordination, memory, and multitasking attributed to class participation, which translated to other areas of daily life such as planning and cooking meals: "[The brain] gets exercise at Dancing with Parkinson's because most dances are more than one step... when they give me the second thing to do at the same time... I notice it immediately."^[P9]

Dance and the Body. Although, participants had difficulty identifying goals for the program, they reported a desire to maintain their current functional status and to slow physical deterioration as motivation for continued participation. Many revealed an understanding of the benefits of exercise on disease specific symptoms and as part of a healthy lifestyle. Commonly identified Parkinson's-related changes in physical abilities included decreased balance, falls, poor coordination, slow movement, tremor and fatigue. Some also described communication changes such as slurred speech and quieter voice.

Participation in the DWP classes helped to offset some of these changes and yielded physical benefits. Specific benefits, such as "it subsides my tremor" or increased strength were sometimes described, but more often participants suggested general improvements in movement quality: "It has led to some fluidity, which might not have been there in the body earlier."^[P1]

When discussing their energy levels in relation to the class, a few participants referred to feeling tired after the class, but cited that class participation made their bodies feel "tuned" and gave

them a “power boost”. They also expressed a feeling of “muscle stretch” and increased flexibility, and appreciated the opportunity to coordinate different parts of their body.

Lasting physical effects from participation in the DWP class were reported by nearly all participants; however, responses regarding length varied from a few hours to several days.

The Emotional Experience. Participants agreed that attending the dance class improved their mood, stating that it gave them something to do, look forward to, and enjoy. They reported feeling more relaxed, “brighter”, and able to “go with the flow”. Participants identified multiple factors for this, including the social interaction with other classmates and the “energy that you create” while dancing. The musical selections and the instructor were also identified as strongly influencing participants’ feelings and mood.

Although frustration due to physical inabilities and embarrassment from being on display encompassed some of the negative emotions that could occur as a result of the class, participants also mentioned that seeing other classmates make progress and enjoy themselves added to their own pleasure and increased the class value: “...you grab a partner and go around, and she smiles, but can’t speak and she’s happy. Emotionally it affects me as well because it’s my benefit to make her happy.”^[P8]

DISCUSSION

This study explores the perceptions of individuals living with PD regarding their participation in community-based dance programs. While other studies have examined the effects of therapeutic dance programs on motor outcomes and QOL measures, this study establishes that the effects of the program are multifaceted and contributes to the understanding of the complex connections between physical, social and emotional well-being in PD. In looking at the participants’ perspectives, the major themes that arose include: improvement of the self and regaining one’s identity through self-management of PD; positive influences of in-class socialization resulting in improved QOL and decreased isolation; and the class acting as a means of communication through music and dance to enhance connection with others and indirectly improve QOL.

Many participants expressed a loss of identity and control, which has been linked to the unpredictable nature of the disease and is common in those living with chronic illness.^{31,32} With subsequent changes in lifestyle and activities following a PD diagnosis, individuals are forced to change the way they perceive themselves and their relationships with others. This can lead to social anxiety and depressive symptoms, which have been reported as predictors for poor QOL in PWP.^{19-21,31} Participants described positive changes in perspective and attitude because of participation in the DWP program, which helped them to take a proactive approach to self-management. These findings support evidence that psychological adjustment to disease, as well as behavioural factors, have an impact on health-related QOL, potentially even more so than severity of disease.^{4,33} Therefore, addressing items related to psychological adjustment such as self-esteem, depression, attitude toward disease and feelings of self-efficacy, may improve QOL.⁴ In addition, the belief that one’s own behaviour and actions can influence health outcomes, may modify the progression of disability and motivate individuals to engage in

behaviours that maintain or maximize function.³³ Feelings of success can alter the perspective that the person has no control over their illness and thus improve psychological adjustment.⁴ Zampieri and Souza observed that individuals with PD who were knowledgeable about their disease, practiced self-care, and engaged in activities, had higher internally-oriented locus of control.³² Our results suggest that participation in the DWP program can facilitate a positive change in perspective and attitude toward a diagnosis of PD, and improve feelings of self-efficacy and self-management of the disease.

The participants also emphasized the importance of being involved and giving back to the community in providing a sense of purpose and usefulness. They stated that the DWP program provided them with opportunities to contribute through fundraising events and public performances, and recognizing each other's successes during class created an environment of mutual support. Sharing what they have learned about PD and helping others may be a way for participants to accept and manage their own changing identity; additionally, having a positive impact on others can help them to derive meaning from a difficult situation.³¹

Research has shown that a decline in physical function leads to a loss of independence and has been postulated to increase feelings of social isolation.²⁰ The DWP program provides an opportunity for individuals in similar situations to become part of a larger group in which they can receive and offer social support. Participants reported that the group class environment provides an opportunity for social interaction in a non-judgmental space. This creates an avenue for improving and regaining a sense of social self in order to increase confidence and happiness, and decrease stress and anxiety. Exercise programs for PWP have been shown to improve various domains related to QOL, with a tendency for gains to be seen more in the area of social interaction and emotional reactions.³⁶ Additionally, earlier studies on dance classes for PWP have revealed increased well-being and QOL.^{16,24}

Participants also described how music and dance in the program provide an alternative method of communication and self-expression on a non-verbal, non-analytical level. Our results imply that these may facilitate social and emotional connections, resulting in improvements in mood. Active music therapy for PD can be effective not only on motor function, but also affect and behavioural functions.³⁴ The Dancing with Parkinson's program may allow for greater expression of one's self and the opportunity to communicate through other means, which may also help decrease feelings of social isolation. Our results help support findings that DWP programs facilitate an improvement in social participation and highlight the value of social interaction as a component of management of the disease process from the participants' perspectives.

Much of the research has evaluated changes in motor impairments, focusing on balance, gait, and endurance before and after dance program participation.^{3,12,13} Interestingly, from the participants' perspectives in our study, physical gains or improvements in areas they identified as issues were not emphasized as important; however, any physical gains may have indirectly contributed to their enhanced social experiences, which were emphasized as important. Despite the importance of physical abilities and mobility on the impact of QOL as illustrated by other studies, many other aspects of life influence an individual's perception of self and sense of fulfillment.^{35,36} Moore et al. found that freezing of gait, a physical manifestation of PD, had a

significant impact on QOL beyond its effect on mobility and gait.³⁵ The authors postulated that the unexpected nature of the episodes, and helplessness that individuals consequently experience, affect PWP on a psychological level.³⁵ Furthermore, social consequences linked with the freezing of gait episodes may be a factor in the avoidance of social interactions. This is supported by literature that proposes improvements or maintenance of physical abilities may indirectly improve QOL by improving mood and confidence, and helping to offset social consequences.^{35,36}

Dance programs for PWP appear to have consistent attendance and low dropout rates, thus facilitating maintenance of functional improvements gained from exercise.^{12,14} This was also observed in our study, as participants reported regularly attending classes for up to two years. Participants emphasized the importance of the social connections they created with their fellow classmates. It may be that DWP classes enhance engagement because of the group interaction, which may also act as a motivator for continued participation and improve overall sense of enjoyment in life. This has clinical implications and should be considered as an approach for treating the non-motor symptoms of PD. One participant noted that DWP uses “happiness as treatment” and suggested this might be useful to consider in developing future treatments or management plans for PD. Physical therapists should incorporate activities where individuals can accomplish “small victories”, as these promote self-efficacy and may potentially increase sense of control over the illness. Future practice must also consider the individual’s perception of PD as a target for therapy, not only their physical or movement impairments, and recognize that modifying the individual’s attitude toward the disease can improve their ability to self-manage. With regard to existing DWP programs, it may be beneficial to engage a physical therapist or other expert to periodically evaluate class activities for safety and efficacy, in order to enhance the motor perspective based on emerging evidence.

There were several study limitations. Our study involved one type of dance program, but a variety of dance programs exist in which individuals with PD or other chronic illnesses may participate; findings may not necessarily be transferrable to other types of classes. However, many components of DWP are common to all dance classes, such as music and partnering activities. A second limitation is the relatively small sample size of ten. Although the number is low, this sample of individuals represented a wide range of age and disease progressions, which should allow the results to be transferrable to other individuals living with PD. It should be noted that new concepts did not emerge following analysis of the tenth transcript. Enrolment in the study from YWALC was lower than that from TSP, so conclusions cannot be drawn on how experiences may have varied based on the diverse demographic areas of Toronto. Differences in location and group size between the two sites may have led to slightly different experiences for participants; nonetheless, there were no remarkable differences noted in responses regardless of the site of participation.

Our results highlight the need for future research to examine the use of dance programs in the treatment of other chronic illnesses and movement disorders, and include caregivers’ experiences in order to provide a third party perspective. The effects of the dance class on the whole person in terms of changes in impairments, activity limitations, and participation restrictions can be studied by employing the World Health Organization’s framework, the

International Classification of Functioning, Disability and Health.³⁷ This could provide another way of uncovering the most beneficial aspects of the DWP program.³⁸

This study provides unique insights into the experience of participating in a dance program from the perspectives of individuals with PD. Inpatient and outpatient physical therapists should consider referring patients to DWP as part of a comprehensive management plan. These programs have the potential to target cognitive and emotional aspects of the disease in addition to the physical impairments. Music and dance provide opportunities for social interaction, self-improvement and non-verbal communication, re-establishing self-identity and a sense of usefulness.

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Table 1: Participant characteristics and demographics

Participant Characteristics	
Sex	
Male	8
Female	2
Age	
60-65	2
66-69	2
70-75	2
75+	4
Site of participation	
YWALC	2
TSP	8
Employment status	
Currently working	1
Retired	9
Living environment	
Lives alone	4
Lives with family/other	5
Lives in community setting	1
Mobility aid use	
None	6
Cane	3
Walker/Rollator	4
More than one	3