



MORE THAN JUST DANCING:

Experiences of People with Parkinson's Disease Who Participate in a Dance Program

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INTRODUCTION

- Parkinson's Disease (PD) is a progressive neurodegenerative disorder characterized by decreased motor ability as well as changes in psychosocial well-being^{1,2}
- Dance programs are emerging as a strategy to address both the physical and psychosocial effects of PD
- Quantitative research suggests that participation in dance programs results in physical benefits: gait, balance, coordination^{3,4,5}
- This is the first study to focus on participant perspectives of the Dancing with Parkinson's (DWP) program and the multi-dimensional effects of dance as a management strategy

Dancing with Parkinson's Program

- The original program was developed by the Mark Morris Dance Group and the executive director of the Brooklyn Parkinson's Group
- The DWP program was developed with the goal of helping people with PD realize their own potential for movement in a safe, fun environment⁶
- Weekly one-hour classes are held at multiple centres throughout the Greater Toronto Area; they are led by a trained instructor and incorporate a variety of dance styles and musical pieces

PURPOSE

The purpose of this study is to explore and describe the experiences of people with PD who participate in a community-based therapeutic dance program.

METHODS

Study Design

- A qualitative descriptive study was conducted using one-on-one, face-to-face, semi-structured interviews
- Ten participants recruited from York West Active Living Centre (YWALC) and Trinity St. Paul's Centre (TSP) who met inclusion criteria were interviewed

Data Collection

- Interviews were conducted in a private space at the centre or in participants' homes, were audio recorded, then transcribed verbatim and de-identified
- University of Toronto, Research Ethics Board, Protocol #30893

Data Analysis

- A content analysis approach with line-by-line coding of each transcript was used, with discussion to arrive at consensus for a flexible coding scheme
- NVivo 10 software was used to organize and manage the data
- Once coding was completed, group debriefs were held to develop themes

RESULTS



Figure 1: Interconnected experiences of DWP participants

DISCUSSION

- Participation in the DWP program facilitates a positive change in perspective toward the diagnosis of PD, improving feelings of self-efficacy and self-management of the disease
- Being involved and giving back to the community helps participants accept their changing identity through helping others
- Non-verbal communication and self-expression through music and dance facilitate social participation and emotional connections
- Regaining a sense of social identity increases happiness and confidence and decreases social isolation, contributing to an overall improvement in quality of life

Physical Therapy Practice Implications

- Consider incorporating peer group-based programs into existing physical therapy practices, as social interaction can be a motivator for continued participation in exercise programs for people with PD
- Include activities where individuals can accomplish "small victories" in order to promote self-efficacy and increase sense of control over the illness
- Acknowledge that an individual's perception of PD can be a target for therapy; modifying attitude toward the disease can improve self-management
- Refer patients to DWP as part of a comprehensive management program; this targets cognitive and emotional aspects of the disease in addition to the physical impairments

CONCLUSION

- This study provides unique insight into the experience of participating in a dance program from the perspective of individuals with PD
- Dance programs provide opportunities for social interaction, non-verbal communication and self-improvement, re-establishing self-identity and a sense of usefulness

"...what about happiness as a treatment?"¹⁰

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What Participants Told Us

"When you get a Parkinson's diagnosis [you] tend to back into a cage somewhere where nobody can see [your] 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."¹⁰

A non-judgmental environment facilitated socialization, which is important because participants reported that living with PD can be isolating. Social interactions varied from casual "chit-chat" to meaningful relationships which extended beyond the class.

"Going to class you're not giving in - you're getting back. You're getting something to help yourself."¹¹

"It sort of gave me a purpose... when I found out that it was Parkinson's I thought that it was just going downhill. And once I joined the program... you walk faster, you look better - there's a glow on your face."¹²

The DWP class helped participants regain a sense of control and purpose in their lives. They learned how to self-modify activities in class and become more proficient in self-management. It also provided opportunities to "give support and feel useful" and positively impacted quality of life.

"To communicate with people who can't speak, or can hardly move, or whose faces are free of any emotion, but you know at a very human level, a very fundamental level, that you are communicating through dance, through music. And I think that's quite profound. I think it emotionally affects me."¹³

Dancing and music were cited as tools for communication. This was especially meaningful for interacting with participants that had difficulty with oral communication or facial expression. Class attendance was enjoyable for participants and also improved mood.