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## Movement for multiple sclerosis: a multi-site partnership for practice and research

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### ABSTRACT

While dance programs for people with Parkinson's disease (PD) have been developed globally over the past two decades, dance programs for people with multiple sclerosis (MS) are just emerging. This article introduces three dance for MS programs and a multi-site partnership that was developed to evaluate and advance a model for dance for MS programs. The program partners convened over 2 days to share program models, consider current and planned program evaluations, and identify unique challenges and promising practices for delivering safe and effective dance for MS programs. This paper presents the findings of this convening and recommendations for dance for MS programs.

**Background:** While dance programs for people with Parkinson's disease (PD) have been developed globally over the past two decades, dance programs for people with multiple sclerosis (MS) are just emerging. This article introduces three dance for MS programs and a multi-site partnership that was developed to evaluate and advance a model for dance for MS programs.

**Methods:** The program partners convened over 2 days to share program models, consider current and planned program evaluations, and identify unique challenges and promising practices for delivering safe and effective dance for MS programs.

**Results:** A set of promising practices for dance for MS programs, including recommendations for partnership, dance and movement approaches, and environmental, physical and psychosocial considerations, was developed by the program partners.

**Conclusions:** These programs suggest that dance may be a useful modality for people with MS. Recommendations are offered to guide safe and evidence-based dance for MS practices.

### ARTICLE HISTORY

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### KEYWORDS

Dance; movement; multiple sclerosis; arts in health

## Introduction

### *Dance for Parkinson's disease*

Over the past 20 years, there has been a rise in dance and movement programs for people with neurodegenerative diseases. Most widely known are those for people with Parkinson's disease (PD). Among this population, these programs are becoming a widely recognized intervention for improving quality of life and overall wellbeing through creativity, social interaction, and improvements in balance, strength, and mobility (Sharp & Hewitt, 2014). In addition to the proven physical benefits, dance also enhances the social, cognitive, and emotional health of people with PD. Literature suggests that dance increases a sense of belonging, self-confidence, and positive mood, while also lowering depression. Participants who engage in these programs have higher levels of motivation and commitment to their own treatment as well as lower program drop-out rates than those who are engaged in traditional exercise interventions (Hackney & Earhart, 2009). Dance for PD programs are being studied to identify impact on self-efficacy and demonstrate the power that dance has to improve the agency of people living with PD (McRae et al., 2018). More recently, research has moved toward consideration of the "values" of dance for PD from the perspectives of the participants themselves (Houston, 2015, 2019). For example, values such as dancer-centered agency can be highlighted by constructing movement patterns that provide structure for people with Parkinson's disease to move differently with intention and creativity (Houston, 2019). Lastly, there is increasing consideration of how different movement qualities, such as bradykinesia and dyskinesia, contribute to dance as an artistic and aesthetic entity. "Parkinsonian movement expands the notion of what dance can be" (Houston, 2019, p. 102).

These developments and findings support dance as an effective intervention, recreational, and lifestyle choice for improving quality of life in people with PD. While Dance for PD practices have garnered a substantial following and evidence for improvements in participant symptoms, there remains a need for similar, but specifically tailored, classes for people with multiple sclerosis (MS).

### *Tailoring the approach to MS patients*

Multiple sclerosis is a chronic inflammatory and neurodegenerative disorder of the central nervous system (CNS), and one of the leading causes of disability in young adults across the world. It is an accumulation of demyelinating lesions in the CNS that leads to a variety of neurological symptoms including ataxia, weakness, sensory symptoms, visual deficits, fatigue, cognitive dysfunction, urinary/sexual dysfunction, and affective dysfunction. These symptoms significantly decrease independence and quality of life in people with MS. In the natural course of the disease, permanent neurological impairment and progression of physical disability become more apparent over the course of time (Filippi et al., 2018). While there have been great advances in slowing the progression of the disease through disease modifying therapies and pharmacological approaches, exercise remains an important tool for managing MS.

Exercise has long been known to have a positive effect on symptoms of MS, including fatigue, loss of balance and weakness (Halabchi et al., 2017; Heine et al., 2015). Due to its creative nature, dance as a form of structured exercise may provide an even greater benefit than traditional exercise. Dance provides a means of balance and motor rehabilitation in a creative and varied format, combining physical, social, and psychological benefits.

Throughout history, dance pedagogies have honed locomotor skills, gait, balance, and overall bodily coordination alongside the creative, poetic and performative practices that define dance as an art form (Krasnow & Wilmerding, 2015). Germane to contemporary dance is the integration of somatic (body-mind) movement practices, many of which look at the development of the whole person as observed and expressed through movement (Eddy, 2017). Dance has been studied as a form of rehabilitation in different neurological disorders (Delabary et al., 2018; Patterson et al., 2018) with promising results, but data on the MS population remains very limited (Mandelbaum et al., 2016).

In the PD population, dance has been shown to improve functional and mobility outcomes exceeding those of traditional exercise programs (Delabary et al., 2018). The international implementation of dance programs such as *Dance for PD*<sup>®</sup> has provided benefit to people with PD including enhanced overall wellbeing and quality of life. In the MS population, a limited number of small-sized studies related to dance have shown promising results, with improvement in Expanded Disability Status Scale (EDSS) scores (Salgado & Vasconcelos, 2010), Timed Up and Go Test (TUG), Dynamic Gait Index (DGI) and Activities-Specific Balance Confidence scale (ABC) (Mandelbaum et al., 2016). A small pilot study also showed positive impact of a targeted ballet program on ataxia and balance (Scheidler et al., 2018).

While dance for MS programs can learn from and build upon the excellent model developed by the Mark Morris Dance Group's *Dance for PD*<sup>®</sup> program, there is a critical need for development of programs for people with MS that are built upon the specific goals and challenges of that population, which vary from those of PD. Although there are some commonalities in the chronic and progressive nature of the diseases, the range of symptoms, experiences, and life disruption is unique. For example, the affects of demyelination (i.e. muscle weakness, stiffness, and spasms, and vision problems) and juggling the relief of remission with the fear of recurrence are unique to MS. The programs presented in this paper aim to fill the gaps in research and in practice protocols by providing models for best practices in dance for MS programs. Each program model is now presented, followed by a set of recommendations rooted in the learning experienced within each setting, shared and developed further through the convening in October 2018.

## Program models

Georgetown University, Scottish Ballet, and the University of Florida each designed and launched dance for MS programs aimed at improving wellbeing for people with MS. A multi-site partnership between the three programs was developed to explore how the foundational understanding of MS and movement can manifest into a best-practice program. Seventeen participants representing the three programs met at MedStar Georgetown University Hospital, on the campus of Georgetown University, and hosted

by the Georgetown Lombardi Arts and Humanities Program, to discuss the promises and challenges of developing Movement for MS programs. Over 2 days the group joined a regularly scheduled Movement for MS class, reviewed similarities and differences between the programs, and took part in a facilitated discussion to determine best practices and develop recommendations. Brief descriptions of each program are presented below, followed by recommendations that emerged from the convening's discussions.

### **Georgetown university**

The Georgetown Lombardi Arts and Humanities Program (AHP) established *Movement for MS*, a class for people living with MS, in November of 2017. The class is offered at Dance Exchange in Takoma Park, Maryland for 10 weeks in the fall and spring, and 8 weeks in the summer. The weekly class is 105 minutes with a ten-minute break near the mid-point. Approximately seven-fifteen people attend each class, which is offered free of charge. These participants are recruited through flyers, word of mouth, the local tri-state MS Societies, and the MGUH Neurology Department's patient education programs. The teaching structure includes a lead teacher and assistant teacher in each class, which allows instructors to accommodate differing functional stages of participants.

AHP's *Movement for MS* program has completed two pilot studies and, as of this writing, is in the final phase of a research study. The program is a partnership with the MedStar Georgetown University Hospital (MGUH) Department of Neurology, and funding is provided by the MGUH Neurology Department and the AHP.

### **Scottish Ballet**

Scottish Ballet launched *Elevate*®, a Movement for MS program, in Spring 2019. As a component of Scottish Ballet's Dance Health program, *Elevate*® builds on the company's prior experience working with dancers with PD and dementia. The program was established in two phases. Phase One, from May 2018-June 2019, involved an extensive development period, including "taster" and focus group sessions and workshops with people with MS and representatives of the MS Society Scotland, MS Revive, and NHS Scotland clinical professionals. This phase culminated in weekly 75-min classes over ten weeks, in Glasgow. Two classes, morning and evening, accommodated differing lifestyles. Through a research partnership with the Royal Conservatoire of Scotland, a mixed methods study was undertaken, focusing on the perceived impact on balance, fatigue, and gait. On average, 10 dancers with MS attended each weekly class. This phase was part of a pilot with funding from the RS MacDonald Trust.

Phase Two, from July 2019-October 2019, involved a second block of weekly classes in Glasgow and an intensive series of sessions in Orkney, where more than 40 dancers with MS participated. More recently, a partnership with Ninewells Hospital and Medical School, Dundee, and the University of Dundee, has developed in advance of classes launching at two further locations.

All of the classes are offered free of charge and are led by a member of the Dance Health team supported by a second practitioner and volunteers. Scottish Ballet's

repertoire serves as a creative starting point for movement, and classes include live musical accompaniment and social time. Dancers are also invited to the company's dress rehearsals and performances to facilitate connection with the greater Scottish Ballet community.

### **University of Florida**

The University of Florida (UF) created *Dance for MS*, a dance class for people with MS, in August 2018. The 75-min weekly class is team-taught by a primary artist in residence, dance faculty and Dance in Medicine Certificate students. To date, three to six people with MS attend each class, which is offered at no charge. Participants are recruited from the UF Department of Neurology's clinic by the clinical faculty members, through regional MS patient information forums sponsored by the MS Foundation, and through direct invitations by the class instructors who visit the clinic and are introduced to patients by partner physicians.

The program was developed through an interdisciplinary laboratory that engaged faculty from the Center for Arts in Medicine and the School of Theatre and Dance, neurologists, physical therapists, occupational therapists, and Dance in Medicine Certificate students in four 2-hour laboratory sessions. In the sessions, participants shared their discipline-based knowledge (i.e. dance, neurology, occupational therapy) and collaboratively designed the class structure. The program is a partnership between the UF Center for Arts in Medicine, UF Health Shands Arts in Medicine, the UF Department of Neurology, and the UF School of Theatre and Dance, and is supported financially by UF Health Shands Arts in Medicine and a grant from the MS Foundation. As of this writing, the first study of the program has been implemented.

### **Recommendations: promising practices for dance for MS programs**

Program leaders from Georgetown University, Scottish Ballet, and the University of Florida came together in Washington, D.C. in October 2018 to share program models, evaluate promising practices and challenges, and to develop a partnership designed to serve as a basis for the development of unified best practices and multi-site research. Each Movement for MS program across the three locations was committed to undertaking tailored research, as referenced above. At the time of this convening, only Georgetown University had completed a pilot study. However, each program shared data in the forms of participant observations, class design structures underpinned by evaluation of dance and MS literatures, and program evaluation results.

The two-day convening resulted in the development of a set of promising practices for Dance for MS programs. These considerations were informed by the completed pilot research findings, program evaluations and feedback, and the cross-disciplinary perspectives of the convening partners, reflecting a blending of medical and artistic bodies of knowledge. They also strongly value and reflect the lived experiences of the program participants. They are intended to guide standardized practice and as well as outcomes in order to develop safe and evidence-based practice.

## ***Partnership***

Partnership between clinical providers who care for people with MS, such as neurologists, occupational therapists and physical therapists, and professional dance artists is key to the development of safe and effective programming, as is partnership with people with MS. Collaboration and consultation with participants with MS ensures that individual and collective lived experiences shape the specific kinaesthetic, physical, social, and emotional approach and content of a class. While dancers have expertise in facilitating movement and conditioning the body toward specific goals, these goals must be defined and guided in partnership with clinicians and participants. Similarly, those facilitating dance for people with MS must understand the unique challenges and risk factors associated with MS. These partnerships should be utilized in program design, oversight and evaluation, as well as the creation of a system for referring individuals into the classes.

## ***Dance and movement approaches***

### ***Creativity and artistry***

Grounding the class in the art of dance, including artistry, expression and mastery of movement, is essential as presented within dance for PD research and evaluations (Houston, 2019; Houston & McGill, 2011, 2012, 2015; Whiteside, 2017). Above all, the creativity and artistry of the class engage participants and provide meaningful and valuable aesthetic experiences. Practicing the art of dance also encourages participants to learn and develop various movement skills, which provides opportunity for exercising body awareness and for developing stability, flexibility, and coordination.

### ***Inclusive approaches to movement***

Movement for MS classes will attract participants with a wide range of abilities. To provide a meaningful experience for all levels of ability, a conceptual approach to dance that allows for this variation is useful. Approaches such as Laban Movement Analysis and other somatics practices go beyond memorizing and executing dance steps by inviting participants to explore movement through focused improvisation, creative prompts, and reflection (Eddy, 2017; Moore, 2004). These approaches allow for individual interpretation and choice, and are particularly useful in designing dance classes for people with MS. They also provide whole-body, three-dimensional movement opportunities, helping participants to regain and maintain range of movement. Movement expressed in the sagittal, horizontal and vertical dimensions of the body and kinesphere can enhance participant core-to-periphery knowledge and connection.

Movement patterns such as brief, repetitive, rhythmic phrases also may improve timing and challenge cognitive abilities in positive ways. These approaches can be applied in dance class structures that may include seated/chair work, floorwork (if collective abilities allow), barre work, standing and ambulatory motion. Participants should always be encouraged and supported in making adaptations to movement sequences to accommodate their own needs and goals. Teaching teams should also include a lead teacher and at least one trained volunteer or staff assistant to model different types of functionality and expression.

## ***Environmental considerations***

### ***Space***

Space must be accessible and supportive of participants' physical needs. Studios should have chairs and/or ballet barres, accessible restrooms, and available drinking water. The location of the studio both within a particular geographical locality and building are also important considerations, including the accessibility by public transportation, and the position of the studios within the building. For example, although Scottish Ballet's headquarters and studios benefit from being easily accessible by public transportation, the position of the studios within the building are less easily accessible. In this case and others, volunteers can provide valuable support by greeting and escorting participants to the studio or program space.

### ***Temperature***

Room temperature must be monitored, as people with MS can be sensitive to heat. People with MS can experience a temporary worsening in clinical symptoms with increased core body temperature, referred to as Uhthoff's phenomena (Opara et al., 2016). It is therefore necessary to have periods of cooling-off and to conduct the class in a relatively cool room to prevent worsening of symptoms.

## ***Physical considerations***

### ***Timing***

Care should be taken to ensure that there are periods of rest throughout the class. Fatigue affects 75% of patients with MS and maintaining activities over a prolonged period of time may be challenging for this population (Braley & Chervic, 2010). Periods of rest throughout the class and intentional variation in the speed and tempo of movement will ensure that patients are able to complete the class without excessive fatigue. Class duration is suggested to range from between 55 and 105 min, with a mid-point break of 10–20 min to prevent participant over-heating.

### ***Turning***

Turning should be carefully approached in dance for MS classes, as dizziness can be an issue for people with MS. If the program facilitator feels that the individuals in the class can safely approach turning, the exploration should begin with slow, multiple-step turns and/or partial turns, such as quarter-turns. Participants should always be provided with alternatives to turning.

## ***Psychosocial considerations***

Psychosocial factors impact physical health and establish a link between social support and anxiety, depression and loneliness. Dance for PD and dementia studies (Houston, 2019; Houston & McGill, 2011, 2012, 2015; Whiteside, 2017, 2020) emphasize the importance of dance as a tool for promoting a sense of community and increasing social connection among program participants. Numerous elements in a dance class, including partnering and feedback can contribute to the psychosocial value of dance classes.



### **Partnering**

Partner dancing (dance styles or sequences designed for two or more people together) enhances connectivity by linking sensory experiences including sight, sound, and touch. This connectivity can be facilitated in seated or standing formats and can foster a sense of community among participants, and also prompt creativity and problem-solving.

### **Participant feedback**

It is critical to elicit feedback during and following classes to ensure that the class is meeting participant's needs and interests, including safety, comfort, enjoyment, physical challenge, creative and intellectual challenge, rest and social engagement. Allowing time for personal sharing before, during and after class also promotes group cohesiveness.

### **Conclusion**

The programs presented in this paper have created a community of practice to advance the understanding and effectiveness of dance programs for people with MS. This work is intended to fill gaps in research and practice by driving a targeted research agenda, and by providing models for best practices in dance for MS programs. Targeted research should investigate the effects of dance for people with MS, based on the specific challenges and goals of MS management and treatment, and through a range of qualitative, quantitative and mixed research methods. These practices and recommendations have future implications for standardized, safe, and evidence-based dance for MS practices.

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No potential conflict of interest was reported by the authors.

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