



WHY DANCE?

A long-term feasibility study to evaluate an existing community dance class for people with Parkinson's using the Parkinson's Dance Science approach

SUMMARY REPORT

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Introduction

Why Dance? was a collaboration between Pavilion Dance South West (PDSW) and the University of Southampton, with research led by Dr Sophia Hulbert and Dr Dorit Kunkel, 2016-2020. Commissioned through PDSW as part of its Parkinson's Dance class roll out programme, funded by Dorset County Council's *2012 Health & Wellbeing Legacy Fund*.

Aim

There were two main reasons to do this study:

1. To find out if it is feasible, to collect and measure long-term outcomes of a community dance class for people living with Parkinson's using the Parkinson's Dance Science approach
2. To explore what long-term impact a community dance class might have on measurements of quality of life?

What do we know already and what will this study add?

Parkinson's is a common and changing condition that affects the nervous system and typically brings difficulties in movement of the body and completing day-to-day tasks (motor symptoms) as well as difficulties in thinking, mood, and wellness (non-motor symptoms).

Dance is fundamentally an artistic experience, rooted in creativity and personal expression. However, its multi-dimensional components offer not just the opportunity of the physical exploration of movement but also auditory, visual, and sensory stimulation, musical experience, social interaction, memory, motor learning, emotional perception, expression, and interaction (Kattenstroth et al. 2010). Thereby providing a truly biopsychosocial model for effect for those living with the varied symptoms of Parkinson's.

Research has consistently shown that dancing can have a positive impact on the lives of those living with Parkinson's. Improvements have been shown in both the motor and non-motor symptoms associated with the condition such as improvements in keeping balanced, walking quality and distance as well as quality of life and feelings of wellbeing.

This research aims to provide insight into the long-term effects that dance may have on physical ability and quality of life for people living with Parkinson's, by delivering pragmatic testing in a community dance class, independent of research protocols and capturing data in a 'real-life' setting. Only with this information can we begin to understand the impact dance may have on the day-to-day lives of those living with Parkinson's in a functional, practical, long-term, and holistic manner.

What type of dance did we study?

All the dancers included in the study were taking part in at least one of four dance classes across Dorset/Hampshire following the Parkinson's Dance science approach to dance for Parkinson's.

The Parkinson's Dance Science approach was co-founded by Neuro-physiotherapist Dr Sophia Hulbert and dance artist Aimee Hobbs in 2011 with support from PDSW. It combines physiotherapeutic effect, research evidence base and the artistic experience of dance specific to the symptoms of Parkinson's. Its aim is to provide a '*Personal, social, artistic and creative dance experience with a theoretical, evidenced and therapeutic underpinning*' (presentation -Hulbert and Hobbs, 2015 - Parkinson's Awareness Day).

The approach aims to provide a fun, stimulating and supportive environment through which people with Parkinson's can explore and develop movement and expression. Emphasis is placed on the joy of movement in the moment, but also aspires to rehabilitate and develop better functional outcomes for the dancers in their everyday lives.

What did the study look like?

People living with Parkinson's assisted in the design and structure of this study. The research and data analysis were led by Dr Sophia Hulbert and Dr Dorit Kunkel from the University of Southampton, with data collection via PDSW, 2016-2020. During this period, people with Parkinson's who were new to starting one of the four roll-out Parkinson's dance classes were invited to take part.

Methodology included a questionnaire when they started the dance class and then posted every three months for up to 2 years. Due to the pragmatic design of the study and people entering at any point, not everyone took part over the whole two years.



"There's a lot of theory behind what's going on but it's not immediately obvious. The obvious thing is that everyone's having fun"

The questionnaire included sections on mobility, freezing of gait and dancer's perception of how difficult they found daily activities. It also included the standardised outcome measure -PDQ39 which measures quality of life specifically for people living with Parkinson's over eight domains - Mobility, Activities of daily life, Wellbeing, Stigma, Social support, Cognition, Communication and Discomfort.

Main findings

Taking part:

- 67 people with Parkinson's newly attended one of the four Parkinson's Dance classes and were therefore eligible to take part in the study. Of these, 46 (22 female, 24 male) agreed to take part.
- A total of 220 questionnaires were returned from all participants over the data collection period including a high return rate, with 88% of questionnaires sent to dancers coming back.
- Learning: due to administrative errors 26% of the data is missing due to questionnaires not being sent out or not returned and all participants had at least one missing questionnaire from their 3 monthly returns. **Despite this, we were still able to meet the aims of the study.**

Feasibility:

- We were able to show that it is feasible to ask people living with Parkinson's who started attending a specific, tailored dance class to complete questionnaires and return them on a regular basis (enabling us to refine the questionnaire pack sent out through this process).
- That it is possible to run a research trial within a community dance class that is 'meaningful and real' outside of a university setting, but that loss of data quality occurs when resources are limited to prioritise the study.

Long term impact and quality of life:

- Initial findings from those dancers with data over one year or more showed a positive effect of the Parkinson's Dance Science approach both physically and mentally.
- Two-thirds of dancers either regained or improved their mobility and freezing of gait. This is against a natural expected decline due to the progressive nature of Parkinson's.

- Activity status represented how difficult people found their everyday activities, which again one would expect to increase over time. This indeed did happen for some, however, just under half of the dancers either showed no increase or experienced a reduction in the number of activities that they found difficult, showing the impact of dance on their everyday lives.
- The PDQ39 showed an overall improvement in all eight domains of quality of life. With a particularly strong effect on dancer's perception of the stigma of their condition and their feelings of discomfort with both showing a significant improvement (the only recorded significant difference) after one year.

What can we take away from this study?

To our knowledge this is still the largest and longest running trial looking at the effect of an ongoing community dance class for people living with Parkinson's globally.

It shows that even though it is possible to embed a research study into an established community dance class for people living Parkinson's and there is a meaningful effect on the dancer, correct funding, training, and resources should be made available to ensure data is of high quality and reliably delivered. With the aspiration that with further research and a greater number of people, we can be even clearer about the results.

Importantly, this study demonstrates that the Parkinson's Dance Science approach has not just a physical effect but also an emotional effect for people living with Parkinson's and confirms that this can improve with regular dancing over a longer time. This is most meaningful when compared to the expected decline in these aspect of life for those living with the condition and suggests dance may be able to help with management of both the physical symptoms as well as how the symptoms are experienced in the long-term.

"You come out of it a couple of hours later, thinking things are pretty good after all"



Thanks go to

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DorchesterARTS



For a full report or more information

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