



Physiotherapist,
researcher and dance
leader **Dr Sophia Hulbert**
shares the journey, design
and thoughts around her
research into dance
for people living with
Parkinson's

Can you see what I feel?



Photo: Lisa Lort, Bournemouth Parkinson's Dance Class, Pavilion Dance South West.

“It’s pleasing, it just makes me feel better.”

“It makes me feel like I haven’t got Parkinson’s.”

“It makes me move freely again.”

“It’s indescribable, I’m just more able.”

These are just some of the reflections of the dancers taking part in a Parkinson’s Dance Science (PDS) class at Pavilion Dance South West (PDSW).

But what does ‘it’ mean and if we were able to understand ‘it’ a little more, could we make ‘it’ even better? Could we tell others about ‘it’ and could we help show the power that dance for Parkinson’s has by having a better understanding of ‘it’?

As a clinical academic and Specialist Physiotherapist in Parkinson’s, I am used to asking questions of my practice and pushing the boundaries between the arts and health. I enjoy challenging and advancing the dance experience we share within our classes. Alongside our dancers and the professional dance artist, Aimee Hobbs, we modelled the PDS approach in collaboration with PDSW, over 10 years. The aim of this approach is to provide a ‘Personal, social, artistic and creative dance experience with a theoretical, evidenced and therapeutic underpinning for people living with Parkinson’s’ (1).

As a collective, we often discuss the strong and advancing evidence base for dance for people living with Parkinson’s alongside our practice and celebrate the physical, psychological and social opportunity for change that dance holds for us all. I was therefore not surprised when the dancers within our class started to formulate their own research question and came to me to find a way to answer it.

“Sophia”, they said, “we love hearing about the physical effects dance has to offer us all, but we feel the research so far is missing the point. We all experience something different when we dance, so measuring us on one outcome, or in the same way, doesn’t acknowledge this. Wouldn’t it be good if you could see what each of us feels?”

So there started the enquiry for a fascinating, enlightening, and powerful research journey for us all – ‘Digital Dancing’ – “Can you see what I feel”: an exploration of the physical ‘experience’ of dance for Parkinson’s.





Photo: Jasmine Taylor, Independent Dance Artist.

It is now well accepted and supported by high quality, experimental trials, combined research through meta-analysis and systematic reviews in both quantitative and qualitative research that dance has a positive effect on the biopsychosocial effects of living with Parkinson's (2).

Changes in the motor symptoms (disease severity, balance, falls, mobility, endurance and posture) and non-motor symptoms (quality of life, fatigue, cognition, mood, feelings of wellbeing) have all been demonstrated in the literature. Whilst this is compelling, the majority of studies to date identify and assess the impact of dance on a specific symptom or experience of the condition. This not only fails to appreciate the multi-factorial nature of the condition but also dance as a mind and body experience, that brings something unique to everyone. For some people with Parkinson's, dance undoubtedly brings improvements in their physical symptoms, but for others it is the connection with other dancers and the emotional feeling that is more important.

“We love hearing about the physical effects dance has to offer us all, but we feel the research so far is missing the point.”

‘Digital Dancing’ is a research project that aimed to capture this unique complexity of dance and try to understand it more. It was facilitated by the University of Exeter with support from PDSW, Attik Dance and funding from the Steve Brown Bursary Award, Dance for Parkinson's, UK.

As a feasibility study, we measured three-dimensional motion analysis alongside interview transcripts, with the aim to see if it was possible to ‘measure what dancers said they felt’. A specific dance sequence was recorded using a 32-point motion capture suit worn by the dancers prior to and immediately following a PDS class. Using an integrated mixed-methods analysis, the biomechanical measures of body movements (walking speed and quality, whole body extension, arm velocity, rotation of the trunk and postural alignment) were matched to the descriptions and experiences dancers gave during an interview following the class as well as a focus group discussion with all class members.

The method of comparing data at the point of analysis allows both the experience and the physical change following a class to be considered in parallel >>

and combination (and not as two separate sub-studies). For the first time, this enabled us to ask; what relationships, if any, could be seen between specific experiences and different body changes following dance activity? Did different physical outcomes drive specific dancing experiences and, vice-versa, did a particular dancing experience/ perspective generate a specific physical outcome?

Perhaps surprisingly, this didn't seem to be the case. It wasn't that those who reported a positive 'feeling' showed greater biomechanical changes as you would imagine or those who showed a greater biomechanical change had a more positive experience. The biomechanical changes observed before and after the class were extremely varied. For example, one dancer showed a staggering 228% improvement in their walking speed, whereas another showed a 10% reduction. One showed a 47% increase in velocity of their arm movement whilst another recorded it to be 33% slower. This pattern continued in all biomechanical variables with some dancers showing what could be perceived as large physical gains and others a so-called worsening of symptoms (as depicted by traditional clinical measures of disease severity, such as gait speed, balance, limb velocity, etc.).

When this data was analysed in combination with the dancers' experiences, unanimously all reported positive feelings following the class. Statements of being "more fluid, open, active" and "feeling happier, freer" or "more relaxed, coordinated, more themselves and less locked in by Parkinson's" were given.

Therefore, a traditional single measure of the physical effect of dance may perhaps, wrongly in this case, be interpreted as a so-called worsening of Parkinson's symptoms, but when considered alongside the dancer's experience, the linearity of cause and effect disappears. It doesn't matter if people physically change in a 'better' or 'worse' way as experience of the change in body movement appears most important to the generation of a positive outcome and the feeling of freedom.

Indeed, the feeling of freedom from symptoms and one's condition following the class was discussed by all the dancers as well as observed by their peers in the focus groups. For some, it was the physical change that drove the perceived experience – for example, "I feel it physically freeing and the emotional and mental changes following leave Parkinson's behind" – but for others even a negative physical experience still gave a positive perception of freedom – "Legs are stiffer, feet are twitchy, aching shoulders but I feel happier, more

positive and free, feeling inspired to exercise and be cheerful."

This supports the notion that dance has a unique, person-centred quality that allows every moving body to experience a newfound movement in a positive way, with freedom being a construct of perceived change, even if that change is in a so-called negative direction with regards to their Parkinson's symptoms.

The growing body of evidence to date has focused on evaluating dance for people living with Parkinson's through its effect on single variables or experiences in isolation. The unique combination of the data sets in this feasibility study enabled dancing experiences to be mapped against physical outcomes to 'see what people felt'. In doing so, it moves beyond the question 'does dance have an effect?' to 'what effect may dance have?' But perhaps more significantly, it raises the question – is it appropriate to evaluate the effects of dance for people living with Parkinson's (or anyone for that matter) using shared measures or isolated measures either on a physical or emotional level if the physical outcomes and perceived experiences are different for all?

Do we risk 'missing the point' of what dance brings; an opportunity for movement experimentation and adaptation in a person-centred way, that might give the illusion of improved or greater movement even if that is not evidenced in the measurable physical outcomes? Perhaps it is important to hold on to this complexity, not only in research design but in our dance practice, to ensure we are offering a holistic, diverse, yet challenging and opportunity-provoking experience for all. Maybe it is only then that we can begin to create the moments of freedom that we all uniquely, but collectively, share through dancing.

Info

📍 @DrSophiaHulbert

📍 @PDSW_org

www.pdsw.org.uk/take-part/health-wellbeing/parkinsons-dance

References

1. Hulbert, S et al. 2020. 'Digital Dancing' – "Can you see what I feel" – An exploration of the physical 'experience' of dance for Parkinson's through 3-dimensional motion analysis. *Complementary Therapies in Medicine*. 52
2. Hulbert, S. 2015. Chapter 2. Dancing with Parkinson's - an exploration of teaching and the impact on whole body coordination during turning. *Doctoral Thesis*. <https://eprints.soton.ac.uk/378386>.