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Including Arts Practices in a Policy Framework to Reduce the Burden of Neurodegenerative Disease: dance for people with Parkinson's

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ABSTRACT

As cases of Parkinson's Disease rise in Europe, there is an urgency to reduce its burden on those living with Parkinson's and on health services. Whilst the search for a cure is on-going, and the use of medication is an on-going experiment for many people, the engagement with non-pharmaceutical interventions is imperative. Under this topic, the 2024 *Policy Framework to Reduce the Burden of Neurodegenerative Diseases in Europe and Beyond* notes the important role that non-pharmaceutical interventions play. In exploring in detail the contribution of arts practices, in particular dancing, this paper argues that they have a potentially impactful role to play as non-pharmaceutical interventions for people with Parkinson's.

This discursive article critically engages with current research discussing what factors are important to be considered for the integration of arts practices – in particular dancing - in a successful implementation of a roadmap for better relieving the burden of Parkinson's. Key points laid out include:

- It needs to be recognised that arts practices are heterogenous and do not have treatment goals, but do emphasise what the person brings to a process. The lack of standardisation and goals are to be embraced, rather than criticised for being difficult to measure.
- The evidence around dancing for people with Parkinson's is not conclusive, yet largely positively framed.
- To increase understanding of what quality of life and relief of burden feels like to people with Parkinson's - and so greater success in implementing arts practices as NPIs in a Europe-wide policy - a broader range of studies from different disciplines need to be used in researching or reviewing this area of work; researchers need to actively listen to what matters to people with Parkinson's and be critically reflective of their own studies consequently.
- The Action Plan for non-pharmacological interventions in the *Policy Framework* is welcomed. Policy implementation needs to happen in consultation with dance organisations operating strategically around Europe, with people with Parkinson's and with those who are underrepresented in Parkinson's initiatives and dance activity.

Introduction

The 2024 *Policy Framework on Reducing the Burden of Neurodegenerative Diseases in Europe and Beyond* is clear: cases of neurodegenerative diseases, including Parkinson's Disease, are increasingly prevalent.[1] There are currently 1.2 million people that are affected by Parkinson's in Europe[1] and as cases of the disease have doubled over a generation world-wide, there is an increasing urgency to reduce the burden of the disease as population longevity and environmental factors potentially give rise to a greater increase in cases in the future.[2] As cases of Parkinson's rise in Europe, the burden is on those living with Parkinson's, as well as on health systems and their services at local, regional and national levels.

The *Policy Framework* suggests that engaging with non-pharmaceutical interventions (NPIs) is a way of helping reduce the burden of neurodegenerative diseases in Europe and beyond. In this article, I offer an argument to focus thinking and enhance policy detail on why and how a specific category of NPIs are not only useful, but also powerful tools in helping make lifestyle modifications and in managing the psychological burden. My discussion brings attention to arts practices that engage people with neurodegenerative conditions. I argue that arts practices have a role to play as NPIs; not as therapies – there is a separate clinical category for arts therapies – but as initiatives prioritising a person-centred approach to creative, imaginative and often relational activity for their own sake rather than for a clinical outcome. Specifically, I examine dancing as a well-publicised arts practice that may contribute to reducing the burden of Parkinson's Disease (commonly known as 'Parkinson's'). I suggest here that this emerging topic of dance and Parkinson's has potential to have impact worldwide upon wellbeing and on conceptions of what health is living with a neurodegenerative condition. I underline that arts NPIs, and specifically dancing, could have a significant contribution to make, but in tandem there needs to be greater critical and multidisciplinary awareness in research studies and reviews to accomplish impactful and long-term integration of arts practices as NPIs. Thus, this article makes a critical contribution to the development of the Policy Framework offering a little discussed, yet potentially impactful area for inclusion within the urgent roadmap for relieving burden of fast-growing neurodegenerative disease.

The cardinal symptoms used to clinically verify the presence of Parkinson's are all movement related: bradykinesia, tremor, rigidity of muscles. Alongside these three, postural instability becomes a fourth major symptom and a range of other, often debilitating, symptoms, which include non-motor symptoms, can intrude.[3] As the disease progresses, quality of life becomes more difficult to maintain.[4,5] Despite knowing what is happening in the brain to produce these symptoms, and several hypotheses as to the cause of Parkinson's,[6] there is no cure at the time of writing. Although there is effective medication for the control of some symptoms, patients often have on-going challenges with complex regimes, dosage, side-effects and its efficacy over time, and so quality of life may lower even with medication.[7] Whilst the search is on-going for a cure and medication is often challenging, particularly as the disease progresses,[7] engagement with NPIs is imperative and dancing is proving to be a popular activity.

Within this article I define the category of arts practices as NPIs and summarise dancing as it is offered to people with Parkinson's. I then give a critical overview of the evidence that points to an improvement in health and wellbeing for people dancing with Parkinson's. I open out the discussion more widely to argue why arts practices, and in particular dance, are important NPIs. In doing so, I bring together a group of studies and discussions that underscore my argument for a multidisciplinary and reflexive approach to establishing an appropriate and rigorous evidence-base and that actively listens to people living with Parkinson's as a priority in study design and in reflection on results and conclusions. This approach, I argue will allow researchers and policymakers to better frame the importance of this field of practices as non-pharmaceutical interventions. Finally, I offer some strategic thoughts to add detail and context to the Action Plan outlined in the *Policy Framework* with specific reference to dance and arts practices.

Arts Practices and Health

I emphasise arts practices here as participatory activities that engage in different ways with the visual and performing arts (such as singing, dancing, painting), with cultural heritages, crafts, design and individual creativity. As I have explained elsewhere,[8,9] arts practices in health and wellbeing contexts can be seen as a separate category to other activities because they engage with the imagination and primarily provoke the senses. As such, they are, what theatre scholar James Thompson[10] indicates, more about 'affect', rather than 'effect'. Although a lot of arts practices can be done alone, I am more interested here in those that are social and relational, which is where 'affect' can be so impactful. I observe that

> arts practices develop places of creative ambiguity where participants meet others, enjoy a conversation, laugh, cry, joke, swap stories, take on challenges, respond to provocations, relax, learn, create, fall in love, feel joy.[8]

These messy bundles of joyous activities are often ignored as potent wellbeing activities in research because of their heterogeneity and the difficulty in categorising and generalising outcomes.[11] They emphasise the process of doing and making, rather than being outcomes-based.[12] Moreover, teaching artists regard participants as collaborators and co-producers, who already have creativity and ideas to offer:

> Participants value the gaze of the artist which, unlike that of the therapist, regards them as people with potential – potential to create, to inspire, to develop – rather than a problem to solve.[12]

Despite these challenges to easily collecting an evidence-base for arts practices in a health and wellbeing context, the field of research in arts and health is growing, as is the field of practice in arts and health initiatives.

Moreover, bodies shaping health and wellbeing policy in Europe have been active in advocating for the inclusion of arts practices as NPIs. For example, the 2019 World Health Organisation (Europe) scoping review of the connection between arts and health concluded that there is potential value in arts practices contributing to core determinants of health, including the treatment and management of neurological disorders.[13] This is corroborated by the two-year U.K. All Parliamentary Group on Arts, Health and Wellbeing Inquiry 2017, which produced a report detailing evidence of where arts practices had an impact on the social determinants of health. The report claimed that "the arts can be enlisted to assist in addressing a number of difficult and pressing policy challenges"[14] in relation to health and wellbeing. The Group went on to lead a year-long review of creative health (including arts practices) in 2023 concluding that creative health is "fundamental to a prosperous and healthy society" and that it should "form an integral part of any 21st century health and social care system" and for creative health to develop there needs to be joined up thinking with a "whole systems" approach.[15] The European Culture for Health Scoping Review[16] concluded similarly that culture (including arts practices) across Europe has an important role to play in creating a more holistic and broader approach to health and social care. It argued that culture could help effectively tackle health promotion and disease prevention, a growing mental health crisis, challenges from an ageing population and the association between ill health and patterns of inequality. Whilst these reviews have substantial limitations in terms of the selection of sources and the subsequent analysis,[17,18] they demonstrate the interest public bodies have in posing the idea that arts practices have a place in health care and social and individual wellbeing. This interest is fuelled by grassroots participation and enthusiasm for taking part in arts activities and the growing number of support organisations for arts activity in Europe that are engaging both with policy makers and with research. (See for example the extensive list of organisations affiliated with Culture for Health EU, which runs into the hundreds https://www.cultureforhealth.eu/organisations/).

There is an overwhelmingly positive mood about the power of the arts and unsurprisingly many advocates within the arts sector for the benefits claimed. As this paper outlines, there are challenges to a straightforward benefit story, but there are voices that are posing constructive critique and solutions in grappling with research in this area, particularly in dance and music.[11-12,17,19-24]

Dance for People with Parkinson's

The Policy Framework notes the important role that NPIs play in relieving the burden of neurodegenerative disease; for example, that "lifestyle modifications, such as…exercise, have been shown to improve overall health" and that the management of good mental health is "vital for managing the psychological burden".[1] The arts practice easiest to see as an NPI for Parkinson's, according to both lifestyle modification and management of good mental health, is the activity of dancing. Dancing is the art practice that when pursued as a pastime, can be taken as exercise, as a social engagement, as an intellectual challenge, as a contributor to wellbeing, as a topic for augmenting education, and/or as a creative activity. Its multidimensionality means that its potential function as an NPI could be varied.

Dance organisations and independent dance teaching artists have increasingly offered tailored dance classes to people living with Parkinson's for over 23 years[25,8] and the demand from people with Parkinson's themselves has meant that there are now classes offered across 6 continents in major cities, small towns and even occasionally in rural locations.

Dance is an umbrella term for many different approaches to moving one's body with purpose, imagination and aesthetic patterning. Many approaches are social, relational and invite participation. Many, but not all, involve a relationship to music. Dancing offered to people with Parkinson's covers a wide spread of these different approaches including dance forms such as creative improvisation, ballet, popping, ballroom, tango, salsa, tap, bollywood, kathak, contemporary dance, musical theatre, folk dances and somatic techniques.

Most specialist programmes work with people's needs on the day and usually do not separate participants out into different groups that depend on severity of disease. This means that teachers will accommodate people's needs by, for example, offering a seated version of a standing exercise, or doing the first few exercises with everyone seated, or having someone contribute in a different way, for example through giving movement suggestions, if they cannot move that day but want to be present. A few large programmes have experimented with creating different classes for different levels of attainment. These have had mixed results. Although it has meant that classes may go at a faster or slower pace, it has also been a source of anxiety because it draws attention to the progression of disease, something that mixed ability classes do not as much.

Many programmes work within a dance form creatively, for example, through movement proposals that focus on one element of the form (for example openness, storytelling, or dynamics), which can be used creatively however disabled a participant feels. Whilst some classes will use an improvisatory format, using an individual's own movement ideas and patterns, others are more didactic in tone with a leader teaching exercises, and in these cases a sequence of movement will be broken down into small sections so multitasking or memory is not such an issue. In describing the variation of programmes, even in this context where a disease is foregrounded, dancing is not standardised or goal driven like physiotherapy is for the alleviation of symptoms. (One exception to this would be the non-Parkinson's specific Dance to Health programme[26] where physiotherapy protocols are integrated into creative movement classes as an intervention to decrease risk of falling in England. It has not had yet the widespread popularity that was proposed). This lack of standardisation and goal orientation is part of why dancing here is classified as an arts practice and not purely as an exercise modality. It is not seen as a flaw or something to be corrected, even though it is a challenge for researchers and arts in healthcare advocates.

Dance for Parkinson's Research

Whilst there has been some research that has examined the relationship between dancing and other neurodegenerative conditions[27-33] by far the most papers have been published on dance and Parkinson's, which complements the superior numbers of specialist dance programmes offered for people with Parkinson's around the world compared to those for people with other neurodegenerative conditions. Many of these programmes have engendered excitement and passion, which in turn generates community advocates and curiosity by researchers.

Most research in this area has concentrated on dance's effect on motor skills, such as walking, sitting to standing, turning, static and dynamic balance, along with motor symptoms, as set out in the Unified Parkinson's Disease Rating Scale subsection III (see the systematic reviews and meta-analyses[3,34-39] as an indication of the spread of RCTs and some other studies). Most likely these areas of assessment have been carried out under the understandable assumption that because dancing is a physical activity it will be the exercise and potential mobility that could deliver the most impact. Motor function is also easier to assess than other elements with standard verified clinical measures, such as the Timed Up and Go test and the Berg Balance Scale. Additionally, some reviews have also, or instead, examined non-motor symptoms, such as cognitive function, depression, apathy, as well as self-efficacy and quality of life.[3,34-36,38-43]

Perhaps understandably, given dancing's status as an arts practice and not a goal orientated therapy, results have been mixed yet in general positive. In a rigorous regard of 20 dance for Parkinson's RCTs, Ismail et al.[39] concluded that the studies "modestly reduced motor disease severity and improved certain aspects of balance". In a more wide-ranging systematic review, Carapollotti et al.[36] likewise suggest that motor symptom severity is improved through dancing, although they also comment that "dance is a complex social experience involving music, learning, and opportunities for self-expression making it difficult to measure its value through quantitative methods alone". In a systematic review solely of non-motor symptoms, Wang et al.[41] concluded that dancing improves cognitive function. In 2024, after a systematic review and three-level meta-analysis Cheng et al.[43] found that mental health and quality of life are positively affected by dancing when compared to passive controls rather than active. Emmanouilidis et al.[38] examined the most studies, both RCTs and others, determining that "dance can, in the short term, significantly improve balance, mobility, gait, disability and quality of life" in people with Parkinson's. Importantly, they noted that many papers argued for an increase in classes to help expand people's ability to exercise and develop wellbeing, as well as aiding in their ability to socialise. In all of these reviews the authors note insufficient evidence for some measures looked at, particularly for symptoms, such as depression and apathy.

All of these reviews and the studies that have been selected have limitations, for example, Ismail et al.[39] warn of low certainty of evidence in dance for Parkinson's studies. Clift et al.[17] warn of uncriticality in arts and health reviews and studies taking evidence at face value. Emmanouilidis et al.[38] and Carapollotti et al.[36] point out that much of the research only applied to people with mild or moderate Parkinson's, and I would add, almost all paid no attention to social, ethnic and socio-economic backgrounds of participants, which might have contributed to a contextual picture of how dance and Parkinson's map onto key social determinants of health,[44] or at the very least give a more detailed picture of who is taking part in dance for Parkinson's research.

It would be fair to say that the evidence that dancing improves Parkinson's symptoms is not conclusive, although there are many indications that it helps in the short term; and as Nakaima et al.[45] point out "transitory and short-term changes may be highly valued and a welcomed relief" for people with a neurodegenerative condition. They also make the point, worth reiterating here, that incomplete data does not mean that it is erroneous, or that there is nothing of interest. Given that dance is not purely an exercise mechanism to better body and mental functioning,[45-49] most of the dance for Parkinson's research featured in many of the systematic reviews only covers a fraction of the aspects of why people with Parkinson's are so enthusiastic about dancing, albeit aspects that are quantifiable, apparent and useful.

Dance as a Non-Pharmaceutical Intervention

Despite research still finding its feet around a complex activity,[8,11,21] this is not to say that dance could not be a popular and effective NPI in a collection of NPIs from which to choose (and choosing to engage is important for an NPI[17]). I would argue that it can be, and we need to expand our thinking about dancing as an NPI from how it is currently portrayed in most scientific literature.

There is an interesting thing which happens when researchers and policy makers start to listen to people with Parkinson's themselves. Often when active listening happens, we have to re-evaluate assumptions as to what is important and what our evidence is telling us. Cultural Policy scholar Eleanor Belfiore noted in 2006,

> Freeing the debate over the social impacts of the arts from the straightjacket of a view that equates acceptable evidence with a narrow conception of performance measurement will mean being finally able to talk meaningfully about all that performance indicators fail to assess. The area of debate this exercise would ultimately free up might turn out to be the very essence of what the arts 'do' to people.[50]

A case in point is laid out in Houston & McGill,[49] one of my own controlled studies with the English National Ballet Dance for Parkinson's programme. After describing the non-significant results from a quality of life validated questionnaire, echoing Westheimer et al.'s[51] findings, we realised that these results did not give the whole picture. From interviews, focus groups and diaries, as well as by asking participants what was most important to their quality of life, it was possible to see what it was that they really valued and that we would have missed this had we just used the validated measures. From there we were able to analyse our findings with this in mind and critique our methods. We concluded that perception of quality of life "is not solely dependent on physical and mental functioning and that quality of life can improve, despite progression of symptom severity"[49] and if we listen to participants about what is meaningful to them then we will gain more useful information about the impact of dance. We conclude:

> Ostensibly, the study examines dance in relation to health, but our results suggest that quality of life through dance is less about health in a narrow sense and more about living life to the fullest. This is not to belittle claims that dancing is beneficial by suggesting that it is merely a fun filled activity – rather the contrary. Dancing as a participatory activity has been shown to be important, particularly for people with Parkinson's as it allows them to create a life that does not revolve around illness but around activities they find interesting, that enrich their lives. In this small way, dancing may allow people to thrive, rather than merely survive.[49]

In other words, dancing is not an exercise modality performed *as* a medicine. It is precisely its *non*-pharmacological make-up that is pertinent here and it should not be thought as a substitute for, or an alternative to, medicine.[46] Dancing escapes from our assumptions about its simplicity as a form of exercise to health. This example shows how for an NPI it is crucial to look beyond how dance performs as a tool in healthcare, to how it raises elements of value to people with Parkinson's.

Our thoughts are echoed by others that have also critically examined their own assumptions in the face of looking for mechanisms that might indicate what works for people dancing with Parkinson's. Notably, Nakaima, Sridharan and Gibson wrote of their evaluation of the Dancing with Parkinson's programme, Toronto[45] where they started with the "simplistic" assumption that the mechanism that benefits dancers with Parkinson's was exercise. They moved from this typical understanding to a more complex one after listening to feedback from the dancers themselves. They concluded:

> A critical learning from this evaluation was the need to rethink what success means when faced with a neurodegenerative disease. The focus of an intervention such as DWP is not to cure PD. Instead, the focus is to ensure that clients feel better daily and feel energized to function through the week and perhaps slow the progression of PD. Physical exercise may be one mechanism by which clients experience a boost in energy; yet, other mechanisms, such as touch, feeling stimulated by the music, and esthetics including "feeling lovely"[52] may have important linkages to health and be fundamental to clients' wellbeing.[45]

My own work[52,8] examining the aesthetic contribution of dancing to a more holistic expression of living well with Parkinson's creates an argument for reframing ideas of beauty, grace, freedom and agency for people dancing with a neurodegenerative condition, which is based on five years of listening to people with Parkinson's who dance across the UK, European Union, USA and elsewhere on how they feel when dancing, contextualising this in relation to the rest of their lives. Unlike previous notions of these aesthetic concepts that prioritised the visual, the beauty, grace and freedom was a felt experience and one that was extremely powerful for some people, one person calling "feeling lovely" her "lifeline"[52]. The importance of these experiences is grounded in the value and meaning they are given. For many, these experiences become crucial in developing a different relationship with their disabling condition.

Fontanesi and DeSouza[53] took the idea of beauty to design an experimental study. Their moment of turning to examine the combination of aesthetic, emotional and physical factors in dancing, away from merely dance as exercise came after a series of three studies on Parkinson's and exercise. Whilst two studies[54-55] of high-intensity exercise found a slowing of Parkinsonian symptoms, with one of those, an RCT, suggested that moderate-intensity – commensurate with the intensity of dancing - had no effect. Meanwhile Bearss & DeSouza[56] published the results of a three-year UPDRS pilot study with dancers with Parkinson's at Canadian National Ballet School's programme that significantly slowed progression of motor and non-motor symptoms (the longest dance study using these measures) compared to age/gender/disease severity matched controls. Fontanesi and DeSouza were left to ask themselves what it was in dancing that allowed the frequent reporting of motor benefits to dance, and the conclusions drawn from Bearss & DeSouza, when rigorous RCT exercise studies show that moderate and low intensity workouts do not slow down Parkinson's progression. This questioning of what the results were telling them led them to enquire further.

The study compared the effects from a dance class with the same people taking part in a matched-intensity exercise class without the factors, such as music, art-making and imagery used in the dance class. Fontanesi and DeSouza discovered significant positive difference in body self-efficacy, a beauty subscale, as well as symmetry of gait and dual task performance. Additionally the dancers' electrodermal activity was higher. They argue that the perspective-transformation of the art practice was not only helpful for wellbeing, but also functionally; the imagery and emotional engagement giving rise to positive attention modulation they surmise enables better walking and multi-tasking.

The study's combination of traditional biomechanical measures with attention placed on aesthetic factors answers Petts & McGill's[23] call for a more appropriate, wider use of different instruments more appropriate to address the phenomenon of dance; a call that is echoed by Chappell et al.[22] and Senter et al.,[24] and also answered by Hulbert et al.[57] in using 3D imaging of movement with eliciting the lived experience of that movement by the Parkinson's dancers themselves. These novel methods, as well as the drive to step beyond common assumptions to probe deeper into a complex activity, allows better understanding of dancing and its ability to function as an NPI.

The push towards thinking of dance as a complex, multidimensional activity encourages researchers to more accurately respond to the needs of people with Parkinson's, which are not necessarily focused exclusively on the amelioration of motor function and symptoms.[21] If an NPI is going to be valuable it needs to resonate with its users. In an ethnographic study of patient life experience in early-stage Parkinson's in Germany and USA,[58] the authors established five themes that are pertinent to on-going care and support:

> (1) people often begin to come to terms with Parkinson's before being diagnosed; (2) accepting Parkinson's is an ongoing process;
> (3) people with early-stage Parkinson's value living in the moment;
> (4) people with early-stage Parkinson's see slowing the worsening of the disease as an important goal; and (5) learning from the first-hand experience of others can be more valuable than scientific information.[58]

Whilst noting that many people with Parkinson's come first to dance because they have read the research studies that indicate improvement in symptoms,[20] with the hope that it may slow worsening of the disease, it is points 3 and 5 which I would like to highlight in relation to dance.

First point 3. Dancing is an activity that brings a participant's focus to the task at hand. This can happen through its cognitive demands[40-41] where dancers will be given choices of how to move, or where conversely they may need to remember a sequence of movement, or where they may need to multitask, moving arms, legs and head through space, as well as doing these movements to a set time pattern and with dynamics indicated by the music or by the teacher. Many classes give external attentional resources[53] to help people move well, such as verbal imagery, someone to follow, a musical pulse, which enable dancers with Parkinson's to focus in on the task. Improvisation, used within many dance programmes, is an excellent activity requiring those who practice to be in the present moment - a sense of giving attention to the immediate action and surroundings - in a different way to concentrating on a set movement sequence. In a study on verbal auditory cueing for people with Parkinson's during improvisation to help train agency, Batson et al.[59] argue that the aim of improvisation is "to stimulate new pathways for motor learning by meeting unexpected environmental conditions arising in the moment and devising new physical solutions as a result". Improvisation scholar Danielle Goldman argued that it allows the dancer to be in a state of "readiness" and creativity.[60] It is not possible to do this well unless a person is focused on themselves in relation to their surroundings and others; in other words, being in the present moment. Improvisation playfully asks dancers to move in non-habitual patterns, and to respond in the moment to new proposals facilitated by the environment, the facilitator's instructions and other dancers. It is an interesting and useful art practice for people with Parkinson's because of their particular challenges with habitual movement patterns, response times and an uncertain environment. It puts the dancer in a space of playful, flexible uncertainty. Despite Parkinsonian symptoms, dancers with Parkinson's can do well in this practice, partly because it gives them the freedom to move in any way they would like to move, and the documentation of my own research[8] gives much thick description[61] of many instances in different dance for Parkinson's programmes of this. Additionally, Batson et al. suggest that for people with Parkinson's, practising spontaneous movement improvisation may allow them to tackle the unexpected movement challenges of daily living more easily.

Point 5, a preference to learning from the experience of others, could be generic to most NPIs that offer social engagement, as dance programmes do very well, often additionally with time after or before the session over refreshments. See studies, such as Bognar et al.[62]; Gyrling et al.[63]; Norton et al.[64], as well as Senter et al.[42], who on reviewing qualitative studies in the area proposed "peer support and insight into living with Parkinson's"[42] as one major theme coming through strongly. Interestingly, there is also research that highlights increased social participation encouraged and supported by engagement in dancing.[8,47,49,62] The research names instances of dance participants founding other creative outlets (such as a singing group) and support hubs (such as a drop-in centre for carers), either alone or as a group, which they would not have contemplated on doing prior to dancing. Dancing as a group in these instances gives rise not just to more social engagement, but to more participation as citizens to ameliorate the lives of others with Parkinson's, as well as their own. McGill et al. write:

> Within dance for Parkinson's research participation may be examined as both a function and an achievement for the participants. Those taking part in the dance sessions are in fact already participating in a social activity. However recent research has also noted the potential for an increase in participation of other activities outside of the dance studio as a result of taking part in cultural programs such as dance.[65-66] As mentioned previously, those with Parkinson's may isolate themselves avoiding participation in other activities.[67] An activity that encourages engagement and socializing with other people such as dance may prove to be a trigger for change in participation levels as defined by the WHO [World Health Organisation].[47]

Following this line of thought, as an NPI dancing may give rise not just to continued social engagement and peer support - so valued by people with Parkinson's themselves - but also social participation where engagement as citizens in the life of their communities might enhance and enrich not just those actors vulnerable to isolation, but others living with Parkinson's too.

In thinking through the implications of point 5, where learning from the experience of others is thought to be more valuable, rather than from scientific information, the statement made by Williams et al.[68] from the Parkinson's UK Edinburgh Branch may help. They state that,

> we are no longer seduced by the prospect of an imminent miracle cure [….] As patients we cannot live without the hope of a life well and positively lived.[68]

They go on to relate how their group members collaborate with researchers and medical professionals to share information as mutual experts and organise activities, such as dancing, as well as train up to be facilitators for the Parkinson's UK self-management course. Williams et al. demonstrate the wish to be active creators of their own lives, despite neurodegeneration. Being active creators means not living in the thrall of possible research outcomes but to actively contribute to studies as partners in research and live out lives where activities are meaningful and joyful. Learning from lived experience may lead, as Williams et al. point out, to a sense of reclamation from being scientific subjects; they use the word 'experts' to describe themselves. There is a plea here for them to be accepted as individuals first and foremost, rather than Parkinson's patients, a theme that comes across strongly in investigating dance. One of the strongest interviews within the documentary film *Capturing Grace*[69] is with Reggie, a Dance for PD regular, who calmly stated, "there are no patients. There are only dancers", a theme that is echoed in many dance for Parkinson's programmes where participants do not want to be reminded of the medicalisation of their identity.[8] It is no accident that in explaining their wish "to avoid living a life that is diminished" Williams et al. quote my own work[52] on feeling lovely dancing:

> There are, besides medicines, 'other ways of addressing the experience of living with a disease that help the person 'reclaim' their sense of being a person (rather than a patient) for themselves'[52].[68]

Dancing is a "joyful",[25] "pleasurable"[70] activity that concentrates not on treating symptoms, but on creating imaginative and embodied ideas, connections, movement. It is a productive, self-affirming activity[71] that allows a person to ignore Parkinson's[48,8] and to explore a more positive personal identity.[42] Although other NPIs may encourage this as well, there are specific interesting factors for the case for dance. Most crucially, it is an embodied activity that encourages a sensual engagement.[70] The resulting pleasure, joy and positive affirmation is grounded in this productive felt sense that is within the body. Given the destruction Parkinson's slowly wrecks on a person's body, dancing can be a highly pertinent activity for reestablishing a more positive relationship with the self.

Some Strategic Thoughts

In this paper I have established that there are confident indications that dancing benefits people with Parkinson's physically, mentally and socially. Yet I suggest that dancing can take its place as a popular and effective NPI precisely because it is not rehabilitative in focus. As an embodied arts practice it allows people to engage socially and through the body and senses, contributing to a "life well lived".[68] In the light of these considerations, I will now turn to ideas that elaborate on the Policy Framework recommendations, namely: to allocate funding; pilot programmes; train and educate; set up public awareness campaigns; collect and analyse data.[1] In doing so, I draw attention to the important nuance needed for the policy framework to be implemented successfully for arts practice NPIs, and particularly for dance for those living with Parkinson's.

1. **Allocate Funding:** Increase of funding for research on NPIs through grants and partnerships with academic institutions is to be welcomed. Unlike many research papers examining dancing for people with Parkinson's, however, I do not want to merely say "more research needs to be done" as my conclusion here. This sentence appears often in papers without much further comment, reflection or reflexivity on the part of the authors. It is imperative that funding goes hand in hand with academic dialogue on arts and health. In their rigorous critique of the WHO Arts and Health report and several others, Clift et al.[17] argue that there are several errors that happen easily in reviews and studies of arts and health initiatives, several of which have been signalled already in this paper. The first error is the assumption that arts and health practices are empowering and thus can change health and economic inequalities and challenge the system in place, which Clift et al. argue is implausible. We need to be realistic in our vision for NPIs and in our claims for what they do; that they exist as useful and even important, powerful, activities to improve the quality of life for individuals and communities. An NPI may change someone's perspective on their life,[52] but challenging economic and health inequalities is a far greater task.

   The second error is to not pay attention to aesthetic elements, the characteristics that separate the activity out from non-art initiatives, as also Nakaima et al.[45] warn about. As I have already noted above, aesthetic elements form a vital role in people's engagement with an arts practice yet are not necessarily configured in many research studies but provide information that is pertinent to why dancing might be beneficial.[8] Clift et al. state that,

   > no attention is given to the characteristics of practice and participation that define arts and cultural activities, as distinct from other forms of social engagement.[17]

   It will be important for research to consider these characteristics. Senter et al.[24] suggest that widening database searches to include the arts and humanities databases, such as JSTOR, ERIC and the International Bibliography of Theatre and Dance Education, for systematic and literature reviews would help integrate appropriate research in this field. Examples of disciplines contributing to the wider picture of dance and Parkinson's from the arts, humanities and social sciences include Communication Studies[70]; Sociology[72]; Dance Studies[46,52,8-9,71]; Ethnomusicology[24]; Evaluation Studies.[21,45] Other examples could feasibly be Medical Humanities and Cultural Studies. Yoeli et al.[12] suggest ethnographic or phenomenological methodologies will help capture the nuance of relational and aesthetic engagement. Other constructs, such as social cohesion, social or cultural capital, might also be worth exploring, they suggest. The above examples offer perspectives that address aspects of dancing together that biomechanical assessments do not, and could, as indicated above, be integrated into mixed methods studies.[23,47,49,53]

Another error is one of "over-inclusiveness", where the arts, music or dance are taken as homogeneous entities, without a thought to the variation of practice, form, culture, pedagogy, or context. Dance is an umbrella term for a variety of practices in many different cultures and contexts, which is important to remember when attempting to generalise, particularly when publicly advocating for "dance" after a positive outcome to a study. This is not, however, to advocate finding out which dance form – or even which step - is more efficacious on Parkinsonian symptoms. To do so wrecks dance as an art form that is characterised by artistic intuition and responsiveness, rather than standardisation and goal orientation.[12]

The last error as laid out by Clift et al. is to acknowledge qualitative study but only to consider the outcomes of RCTs as robust enough evidence on the effectiveness of arts as health interventions. In the field of dance and Parkinson's most systematic reviews concentrate on traditional study designs, such as RCTs, and only look at quality of life through measures, almost always the PDQ39 questionnaire. Only a few acknowledge qualitative study,[36;38] and even fewer use those studies.[42] As this paper has already noted, researchers and policy makers need to look wider than medical-related proof mechanisms, such as the RCT, to obtain a more detailed understanding of the arts practice.

Clift et al.'s recommendation is therefore that,

> the field must rely on rigorous systematic reviews involving careful quality assessment of both quantitative and qualitative studies. Such rich, grounded reviews will provide nuanced conclusions which recognise the complexities of cultural context, research designs and methods, participant involvement, the role of artists and the artistic process, and finally, the nature and seriousness of the social and health issues addressed.[17]

Added to that I would recommend that invigorating academic dialogue and collaboration amongst disciplines is present alongside funding for research studies so that the full potential of arts practices, including dance practices, is recognised. The added incentive to conducting dialogue and collaboration is increased understanding across methodological divides and disciplinary areas for the subject matter under discussion.

2. **Pilot Programmes:** To implement pilot programmes for dance and other arts practices for people with neurodegenerative conditions requires collaboration and partnership, not only with regional healthcare providers, but also with people living with the condition in question, as well as arts organisations and independent artists. Arts organisations not only know their art form well but are often well versed in strategic positioning of that art form in relation to engagement and participation of local communities. For example, access to dance programmes requires knowledge of geographical spread of activity and knowledge of areas where there is none. Some European countries are better equipped with classes than others due to a more embedded and enhanced dance infrastructure. What needs to happen is a mapping of where programmes are offered and identification of any areas where there are no programmes within easy reach, and other needs, such as transport, to allow a pilot programme to flourish.

   An example of this working is in the UK where a Google map was set up by People Dancing, the national strategic support organisation for participatory and community dance. Having identified two areas of England were lacking any offer, People Dancing raised funds to implement regular classes in these areas. For this to be replicated elsewhere in Europe, I recommend working in tandem with European Dance Houses which have a strong pan-European network and make up the infrastructure and strategic knowledge to support dance artists working in each region.

   Additionally, since the Covid-19 pandemic, many arts organisations have integrated learning in how to facilitate high quality, safe online dance sessions[38,73-75] and this learning now needs to become part of how dance artists and their health partners engage with people with Parkinson's, who are not always able to travel to classes.

3. **Training and Education:** Arts organisations with a strategic and training remit will be enthusiastic partners for the training and education of healthcare professionals on the implementation of NPIs. For dance, the European Dance Development Network, made up of key European Dance Houses across the continent of Europe, will be a useful network, as will strategic support organisations and arts companies with deep experience of delivering this work, and of collaboration with external partners and those with neurodegenerative conditions. Examples of these organisations could be People Dancing (UK), Da Po Pa (France), Balettakademien (Sweden), CDC Bassano del Grappa (Italy), Scottish Ballet (UK).

   Dance teaching artists also need and want training. Dance for Parkinson's work can be emotionally powerful and participants may want to rely on the class for maintaining and supporting their wellbeing – many go to more than one class a week if they are on offer - so it is vital that dance teaching artists are educated to work with this population, as well as in their craft. Currently there are a few training and development programmes available internationally, although there is not a geographically wide spread of training initiatives. An online collaboration between People Dancing and Dance for PD is on offer internationally to those who want to take a first step into learning more. In-person training and continuing professional development courses are then offered by those two organisations, (People Dancing in Leicester England, Dance for PD in New York and sometimes internationally), as well as, for instance, Dance Well, based in Bassano del Grappa Italy. Other countries in Europe may have occasional workshops for dance artists. Whilst training is only a first step in securing high standards, it is an important first step in a largely unregulated sector. Teachers who have been trained or have gone through extensive professional development are usually very happy to explain their training to their clients and often advertise it.

4. **Public Awareness Campaigns:** Public awareness campaigns can be very good to bring general awareness of an initiative. With dance, it will be important to achieve a tone that does not pander to dancing stereotypes. Many are fearful of dancing because of assumptions they carry about the art practice. Dance is commonly seen as a young person's activity, mainly for girls and young women, and one that is virtuosic. These assumptions often stop people trying out dance as an activity of choice. Added to this, paying for classes, transport, care and other costs such as specialist shoes can also prevent universal access.[38] One observation coming out of my research[8] is that many come to dance for the first time having been diagnosed with Parkinson's and see it as an opportunity they were either denied, have not revisited since childhood, or did not think it was for them before. This includes many men trying out dancing for the first time aged 70 or 80. To encourage first-timers it is important to allay fears linked to virtuosity (the classes are tailored for older people with neurodegeneration), or costume (there are no requirements), as well as discomfort regarding gender. Some dance artists have advertised male-only Dance for Parkinson's classes, very like those for a much younger generation. Partners are often the ones to nudge men with Parkinson's into trying out a dance class, and the utilisation of partners, family members or friends can be useful here. Some dance organisations have highlighted the dance classes as arts education, as good exercise, as an opportunity to take part in research. These angles have often appealed to men who feel slightly apprehensive about taking a dance class.

5. **Data Collection and Analysis:** A centralised data collection point to identify best practice would be very welcome. As noted in point 1 it will be important to create a database that highlights arts practices thoroughly, rather than partially. It should also include different pedagogical practices, and those that are appealing to populations underserved by arts activities and by Parkinson's support networks. Research on these practices, and pilot interventions featured in the data base should consider diverse groups. Healthcare and research have specific challenges concerning care and participation. For example, research studies on Parkinson's tend to attract more subjects from middle class and white populations,[76] additionally, black identifying Parkinson's patients are being diagnosed at half the rate as white patients.[77] Although the picture is more mixed in the arts, white identifying people are more likely to engage in arts activity[78] and research shows that areas of high deprivation are less likely to participate in the arts.[79] It is no surprise then that leaders of dance for Parkinson's programmes are trying to actively find ways to achieve more diversity.[80] For Dance for PD in New York, this has included hiring Spanish and Mandarin-speaking instructors and fundraising to provide microgrants to underserved communities to start their own dance groups.[80]

6. **Integration of dance into health and social care systems:** The integration of dance into health and social care systems is not in the Action Plan for NPIs. I would like to mention this, however, because whilst most NPI activity will take place in communities, there is also scope for it to happen within health and social care structures and could be considered as part of the Action Plan. There are some reasons for it not to be integrated,[12] which partly have to do with people with Parkinson's wanting an experience that is not connected to the medicalisation of their lives, and because there are no treatment goals or outcomes in art practices, as discussed above. It is a complex proposition to integrate and yet there are some excellent examples of where dance has been embedded into, for example, hospital routines. See for instance, the long term, person-centred dance work happening for Cambridge University Hospitals NHS Trust,[81] or in Liverpool's Alder Hey Children's Hospital.[82] The trust by clinicians and management to allow this sensitive and often emotionally powerful work to happen on wards and in other hospital spaces has been crucial to its longevity and success.

   Trust and belief in the work is not easily won in a time pressed, treatment-focused context with very ill, fragile patients. This is why it is gratifying to see more research and evaluation happening, and research at the level of Randomised Controlled Trials is often required by insurance companies or National Health Service. But more appropriate and relevant research needs to be rigorously carried out, as point 1 established. This will include qualitative work, as well as measurement studies. Health and social care services need to recognise that NPIs, such as dancing that are not medical, need to have a variety of appropriate modes of investigation to grasp their feasibility, value and quality.

   Social prescribing is one approach that has some traction around Europe as a pathway to integration into health and social care systems. By precuring interest from health care trusts and other area health and social care bodies, arts practices, including dance for people with Parkinson's, are highlighted to patients as possible complimentary activities within their health care plans, or indeed, are activities that patients are referred to by their primary health care provider or social care worker.[83] People with Parkinson's then can have access to dance in a way that they may not have had before, and their care is tailored to their interests and overall wellbeing. The challenges to social prescribing are in funding the arts practice properly – at the very least funds need to cover hire of space, wages for dance artists, assistants and musicians – and for all stakeholders to recognise each other's different modes and pace of operating. There is also a tension between labelling an arts practice as a complimentary therapy in health care, and acknowledging that an arts practice will behave differently to a medical intervention, as discussed above, and allowing it the space to breathe as its own entity and on its own terms.[12] Nonetheless, social prescribing seems to be an approach that is becoming more popular to move the shape of arts in health care provision forward.

Conclusion

Any policy to reduce the burden of neurodegenerative disease must take into account the challenges of implementation and optimisation for each specific NPI, as outlined above in the case of dance for people with Parkinson's. In order to maximise effect, it will also mean consulting dance professionals, as well as people with Parkinson's themselves. It might be the case that specific advisory groups are set up with representatives from both arts and Parkinson's communities, including representatives from underserved communities. Reducing burden will only happen if everyone is part of the conversation as to what works for them.

Conflicts of Interest

The author has no conflicts of interest to declare.

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