Performing With Parkinson's: Leaving Traces

Hanna Pohjola, Eytan Sivak and Åsa N. Åström.

ABSTRACT

This article aims to explore the experiences of eight dancers, who have Parkinson's disease (PD), with dance as a performative form of the arts. The data of this qualitative research consists of a semi-structured online questionnaire and a focus group discussion. The data was analyzed using inductive thematic content analysis and approached in an abductive manner in the context of social identity theory. Two main themes emerged from the analysis: embodied social connectedness and de-medicalization of PD.

The current study emphasizes social factors regarding identity while performing with PD. The findings indicate that the dancers' experiences of watching and being watched refer to a communicative body and its dialogical relationship with other bodies. In conclusion, dancing is experienced as an embodied language with which to communicate, allowing the individual to explore how to become visible in a social environment without one's social identity being tied to PD but with one's personal identity. Furthermore, the core of the performative experience is artistry, defined as a limitless entity that metaphorically leaves traces, connecting us as human beings. However, further studies with a larger number of participants would be beneficial.

SAMMANFATTNING

Syftet med den här artikeln varer att utforska erfarenheterna av åtta dansare med Parkinsons sjukdom (PD) om dans som performativ konstform. Data från denna kvalitativa forskning bestårod av semistrukturerade elektroniska frågeformulär och fokusgruppsdiskussion. Data var analyserade med induktiv tematisk innehållsanalys och närmade sig på ett abduktivt sätt i samband med den sociala identitetsteorin. Två huvudteman identifierades i resultaten av analysen: förkroppsligad social anknytning och avmedikalisering av PD.

Den här studien betonade de sociala faktorerna angående identitet när man presterade med PD. Fynden indikerade att dansarnas upplevelser av att se och bli sedda refererade till en kommunikativ kropp och dess dialogiska relation. Sammanfattningsvis upplevdes dansen som ett förkroppsligat språk att kommunicera med och att utforska kring hur man blir synlig i en social miljö utan social identitet relaterad till PD utan snarare med sin personliga identitet. Kärnan i den performativa upplevelsen var konstnärskap som definierades gränslöshet, som lämnar spår som förbinder oss människor. Ytterligare studier med ett större antal deltagare föreslås dock.

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Introduction

Parkinson's disease (PD) is a progressive, neurodegenerative movement disorder that is often accompanied by impaired balance and walking, leading to a reduced quality of life (Earhart 2009). Other common symptoms include tremor, bradykinesia, muscular rigidity, slowness of movements, and challenges in coordination (e.g., Houston 2019; NIH 2022). In Sweden, approximately 18,000–20,000 persons, mostly over 65 years old, are estimated to have PD, and every year, some 2,000 Swedes are diagnosed with PD (Fritz 2021).

Research investigating PD has tended to focus on different aspects of well-being (i.e., physical, psychological, and societal outcomes) and the benefits of social participation in various dance interventions. Despite the growing research interest in dance and neurological diseases, such as PD, there is a lack of understanding about the specific factors and pathways through which dance art mediates its therapeutic effects, especially on dance as a performative form of the arts (e.g., Chappell et al. 2021). Therefore, in this article, we aim to explore the experiences of people with PD with dance as this kind of art form. The subjective experiences of eight dancers with PD are described in the findings presented here. A survey and a focus group interview were used to acquire the meanings associated with the experiences of performance and the process of performing. The data was analyzed in an abductive manner in the context of identity, a concept drawn from social psychology. First, we introduce PD in general and the previous relevant research that has investigated dance in the context of PD. Additionally, we provide a theoretical background for our proposals. Next, we describe our study design, methods, and findings. We conclude this article by discussing our findings in relation to previous research results and highlighting our study's significance.

Background

Parkinson's disease and identity

Over the past two decades, there has been an increasing interest in community-based arts and health interventions related to different serious neurological diseases, for example, PD, *multiple sclerosis*, and stroke (cf. APPG 2017; Fancourt and Finn 2019). At present, most research on the effects of dance has focused on PD (e.g., Sharp and Hewitt 2014; Shanahan et al. 2017), and now, convincing evidence indicates that music-based movement is a promising, feasible, safe, and effective adjunct therapy for individuals suffering from PD. Dancing inherently combines cognitive movement strategies, cueing techniques, balance exercises, physical activity, and enjoyment of moving in time to musical rhythms. Significant improvements in balance, gait, and functional mobility have been found in dance-based interventions for individuals with mild to moderate PD (Earhart 2009; Patterson et al. 2018; Carapellotti, Stevenson, and Doumas 2020).

The presence of a physical impairment and a disability not only imposes concrete limitations on the physical activities of daily living but may also create a kind of obstacle to an individual's social identity and agency (Smith and Sparkes 2004; Coleman-Fountain and McLaughlin 2013; Nolan

2013). It has been postulated that dancing may offer an innovative way to overcome these challenges. For example, a recent review on articulating the aesthetic, artistic, and creative contributions of dance to health and well-being across a person's life course suggests that the key contributions of dance can be presented with seven interrelated factors: embodiment, identity, belonging, self-worth, aesthetics, affective responses, and creativity (Chappell et al. 2021). It has also been claimed that PD dance classes are experienced in a social context through the importance of community, feelings of togetherness, and the ability to compare oneself with others, leading to increased self-esteem and joy (Gyrling, Ljunggren, and Karlsson 2021). Thus, the impacts of dance on the daily lives of people with PD are reflected in a positive way and often described as a sense of liberation, enhanced confidence, as well as an enlarged belief in their abilities, greater flexibility, self-acceptance, and happiness (Bar, Czamanski-Cohen, and Federman 2021).

A serious illness such as PD generally represents a comprehensive life change where the subjective identity is one of the key elements allowing the sufferer to adapt to the illness. This is apparent in previous research conducted on PD and identity. For example, after being diagnosed with PD, a person's identity may be challenged in many ways, as specifically addressed by Sheldrake et al. (2022). Three major themes emerge from their research on the identity process after the diagnosis: (a) attempts to convey, maintain, and negotiate identity; (b) resistance to a disabled identity; and (c) the centrality of an occupation and social roles in negotiating identity (Sheldrake et al. 2022). As PD is a progressive neurodegenerative disease, it is vital to understand that these aforementioned processes with the identity may exist as a continuum as the disease proceeds. Therefore, as emphasized in the systematic review conducted by Soundy, Stubbs, and Roskell (2014), it is crucial to understand the importance of maintaining, retaining, or developing social identities that are essential for the patient's well-being and can provide hope for persons with PD. Additionally, it is important to be aware of the factors that prevent or can facilitate these processes (Soundy, Stubbs, and Roskell 2014). Wieringa, Dale, and Eccles (2022) have highlighted the need to empower a patient to self-manage one's illness as a way of mitigating the effects of PD and supporting the patient's future well-being. In other words, for an individual living with PD, the disruption of one's identity has impacts on one's self-value and sense of self-coherence. For example, it has been suggested that healthcare professionals should appreciate the complexity of the adjustment process, which is related to being able to maintain a coherent sense of self, feeling in control, and having a positive mindset (Wieringa, Dale, and Eccles 2022).

Identity in PD and social identity theory

Most dance-based studies (introduced earlier) on PD were conducted in group settings (as dance classes), where dance was designed as an intervention method in the contexts of rehabilitation, re-creation, and/or social participation. Instead, in this article, we are interested in examining the subjective experiences of what it means to perform as a dancer in a dance company that is based on PD. Thus, the theoretical framework for the interpretation of the data revolves around the social psychological views on personal and social identities.

Consequently, personal identity refers to those qualities that distinguish a person from others, enabling uniqueness, while social identity refers to the traits that the person shares with other group members (Hewitt 1991, 127–28; Burr 2004, 94; Jenkins 2004, 4; Layder 2004; Burke and Stets 2009, 127–28). In more detail, the concepts of self and

identity can be defined as complementary to each other, with slightly different nuances. In short, the self is located in the social field that is polarized into the psychological level of the subject, while identity is situated socially. Despite the different nuances inherent in the concepts, they form a close symbiotic relation, owing to their social origin (cf. Freeman, Adams, and Ashworth 2015, 191–94; Pohjola 2014). This emerges from the social identity theory (SIT) postulated by Tajfel and Turner (1979; 1986), suggesting that membership in a social group has an impact on a person's own sense of identity through the internalization of perceived social identities.

Although SIT was initially developed to understand and explain intergroup phenomena, it is now commonly used in researching social support and well-being (e.g., Haslam et al. 2008; Praharso, Tear, and Cruwys 2017). One possible explanation about the benefit of SIT is the access to the psychological resources within the group membership that might offer a possibility for one's self-definition and provide a foundation for meaningful interactions with others (Jetten et al. 2014). A person's life change and transition can also be approached by means of an extension of SIT, which refers to a more detailed framework called the Social Identity Model of Identity Change (SIMIC) (Jetten, Haslam, and Haslam 2012). In more detail, SIMIC emphasizes the social processes that influence a person's adjustment under the conditions of a life-changing event or a chronic illness and consider how group membership can protect one from the potential harmful effects of identity loss or change (Jetten, Haslam, and Haslam 2012).

Methods and materials

Data and data collection

The data presented in this article consists of a semi-structured online questionnaire and a focus group discussion (e.g., Kitzinger 1995; Ochieng et al. 2018). We selected these different data collection methods to provide inclusive participatory ways that allowed the participants to respond in the way that each one felt the most appropriate. The methods were also chosen to complement each other in order to obtain a deeper understanding of the phenomena, that is, experiences of performing with Parkinson's. The semi-structured questionnaire was sent to eight dancers who had recently performed with *Kompani Parkinson*. Consisting of 6–15 dancers, the group performs both nationally and internationally. The choreographies are structured during the dance classes; different themes, ideas, and movement materials are devised, together with inputs from the dancers. Improvisation tasks and choreographed materials are also combined. The whole group, comprising both teachers and dancers, perform together on stage (see, e.g., https://vimeo.com/manage/videos/706099491).

The semi-structured questionnaire (see Table 1) consisted of background information questions (six in total, two with possible comments) and open-ended questions (seven in total). Seven respondents filled in the complete questionnaire, and one respondent only answered the closed questions (i.e., background information). The open-ended questions were designed to map the whole artistic process (i.e., examining aspects of the PD classes, rehearsing the choreography, and performing, as well as the dance teacher's role in the process). All respondents (female and male) were over 60 years old. They had started dancing 0–6 years ago and had participated in both remote and dance studio-based classes. Many of them were dancing once a week (62.5%); others were doing so more often (27.5%). Most respondents also danced at home, practicing the exercises learned in the dance lessons or merely improvising by themselves.

Six of the dancers continued to participate in the group discussion. The discussion was based on their observations related to the responses gathered from the questionnaire and on their previous international

performance. The focus group discussion data was collected by ES, who also transcribed and translated the text (i.e., from Swedish to English). The discussion was prompted by open and mostly closed questions, as well as clarifying and leading questions. The speaking turns varied from a participant's single comment to the whole group's dialogue. The (approximately) 45-minute discussion was recorded using a recording device, with a video camera as a backup. The transcripts comprised 16.5 pages, with a total of 6,113 words (Times New Roman, 12-point font, 1.5 line spacing). The translated original quotations from the transcripts are presented here in italic font and/or as separate indented paragraphs. Owing to space limitations, only excerpts of the English translations are included. Due to the small sample size, the original quotations are written without any identifying content to ensure the anonymity of the dancers.

Data analysis and interpretation

The transcribed questionnaire responses and group discussion were evaluated using inductive thematic content analysis (e.g., Braun and Clarke 2006). One of the researchers (HP), who was not previously familiar with the dancers, conducted the analysis in three stages. First, the data was read several times and then abridged into shorter paragraphs, which were then coded into several categories. The questionnaire responses (i.e., to the seven open questions) and the group discussion were analyzed separately at this stage. Second, the coded material (69 units in total) from the group discussion was arranged into subcategories (five in total) that were further abstracted by reviewing, defining, and naming common themes (see Figure 1). Finally, the data from the questionnaire responses and the data from the group discussion were combined.

The findings from the analysis are presented in the following sections under two main categories: (1) Embodied social connectedness and (2) Leaving "Mr. Parkinson" aside. Both themes were analyzed in an abductive manner to obtain a theoretical framework. Thus, the data was analyzed according to its content. Since the participants emphasized the importance of membership in a social group, the data was interpreted separately, based on SIT.

Findings

Embodied social connectedness

The participants explicitly described the difference between dance classes and the process of performing. They highlighted the fact that classes that were aimed at a subsequent performance increased their *ambitiousness and excitement.* Additionally, their choreographic class and performances were perceived as strengthening their sense of belonging to a community as the *"anxiety" associated with performance was shared: We are scared together, we stimulate each other, we laugh, we feel the anticipation – it is very exciting and fun.* These above excerpts suggest that the so-called regular class and choreographic class have different areas of focus and meanings, according to the respondents. Generally, it is stated that the dance class encourages the concept of community and celebrates its voluntary and occasional nature (Houston 2019, 164). This distinction is clearly presented in the data. On one hand, PD classes were viewed as occasions where the participants considered themselves individuals. On the other hand, in the data as PD classes were viewed as occasions where the participants considered themselves individuals. Instead, the group that aimed for performance was defined as having tighter *cohesion and responsibility,* especially on stage: *On stage, you take full responsibility because we are part of the whole.*

The most meaningful aspects of performing seemed to be the challenge, excitement, and communication with the audience and the possibility to spread the joy of the dance: *Feedback from the*

audience and that you could touch them. With your dance. While performing, the dancers experienced joy, a boost in their energy levels, increased self-confidence, and pride from the audience's positive response. One dancer wrote:

> Yes, as I said, I did not know anything about it when I started the dance. But it has been insanely fun to train before the performance – and even more fun to perform! Something happens to yourself – it feels almost electric! During the dance sessions, I feel safe and can be myself. During the performance, I become something more than myself – the feeling that I can become anyone is tickling and adds a zest for life. It may sound big, and yes, it's big! It is also the experience of: Yes! We did it – I did it!

The dancers also emphasized how the communication among the group members increased, with a deeper interrelated focus on one another while performing. Interestingly, this also seemed to enhance their artistry, as evident from this excerpt: *we interpret each other, and the interaction becomes very beautiful*. In the data, dance as an art form and artistry appeared in several different ways. A participant stated that the art must originate from *an interaction, and [you must] find your own angle within it.* Another respondent believed that artistry emerged *through the focus of movements*, while the third one said that artistry manifested itself *as an interpretation, an expression, between music and movement*. Other dancers added that artistry was not only an interaction within the group but extended beyond any physical capacities or physical impairments, as reflected in the following excerpt:

> But when it has to do with artistry, there are no kinds of boundaries, so there are no hindrances. In other words, if I feel a problem in my movements, I don't need to experience…. The artistry gives air, gives space, gives room, or gives possibilities. It is something different. … / … There are no hindrances. The artistic part can grow. Even if we get stiffer, the artistry can still grow. When we look at each other, how the others do some dance, maybe you do not look at the movements, you look at the artistry, then in some way, it becomes a whole.

The artistry could also be found in the participants' answers about the subjective importance of dance. In detail, the meaningfulness of dance was described as *joy, passion, possibility of (emotional) expression, social and human contact, harmony, feeling able-bodied, and enhanced well-being*. One participant summarized these concepts as follows:

> To dance is to let go of everything else and exist in the moment. To dance is to meet oneself and to meet others in a strong community. In the dance, it often has to cope with a stiff and awkward body – the dance helps me to get into better harmony with myself. The dance gets me in a better mood – I become happy when I dance.

Thus, the choreographic process was perceived as ranging from the actual dance lessons, the design of the choreography, and the actual performance to the feedback received from the audience. This process emphasized creativity, group identity, and feedback, that is, the experience of a sense of achievement. Both the processes of performing and the actual performance, were viewed (positively) as challenging yet rewarding. The experiences of anxiety, daring to go onto the stage, the thrill of anticipation, and overcoming the positive tension were addressed in the paradox of security and insecurity that teased oneself in a fun way. The importance of the audience and the

relevance of the feedback received from them (e.g., applause and personal greetings) were emphasized in the data. To summarize, receiving feedback was essential, as one dancer stated: there you get something back, that [the performance] has been appreciated. Interestingly, the data suggests the importance of kinesthetic intersubjectivity in the process of performing and actual performance. This could be regarded as a contribution to self–other relatedness and shared experience in a nonverbal way, focusing on an embodied social connectedness.

Leaving "Mr. Parkinson" aside

Importantly, dancing together with the group – formed by other dancers and teachers – offered not only security but also feelings of being supported. The support and security within the group were also described as constituting an essential part of a successful performance. It was emphasized that within the group of peers, *one dared to somehow be oneself and to take the step that one struggled with*. Thus, most of the dancers who participated in the group discussion highlighted the body's ability: *we are not hampered by our disease, but we can function; we can function despite it, in our own way.* Thus, the body was perceived as "differently abled" instead of "disabled." However, the experiences of inclusion varied. Some dancers felt that they were getting their "voices heard"; others associated the disease with exclusion from society, as reflected in the following somewhat complementary excerpts:

> A: They (the dance students who performed with the group) really blended in with us who are older.
>
> B: Oh yes, it was far beyond our expectations. You may have an attitude [toward someone] when you are older and have Parkinson's.
>
> C: I am thinking about ABBA's new song, "Don't shut me down," that we still kind of…. You get used to, in some way, that when you are sick, or I think so in any case, that you are a bit… kind of excluded.
>
> D: We are not excluded.

The new form of being and communicating through dancing enabled the dancers to possibly create an identity that they desired to present to others – an identity unrelated to PD. According to our understanding, for some participants, the core of identity had suffered a blow by being categorized as having PD, and they had experienced a constant struggle to prove that they were still the persons they once were, before meeting "Mr. Parkinson." Thus, dancing represented a sense of wordless peer support and social belonging, in which the disease itself was de-medicalized, *as only dancers were present*:

> It is, maybe, when you dance that you can leave Mr. Parkinson there (pointing to a far corner of the room), and suddenly, you are yourself again.
>
> It is partly that dance helps me to train my body in terms of mobility, balance, and concentration. It is also the experience of doing it together with others with similar conditions. It's quite rare that we talk about having Parkinson's disease, but there is a sense of belonging within it – we understand each other, encourage, and support and help each other – but we focus on dance.

During the group discussion, the participants specifically addressed how they felt about one dancing exercise, that is, mirroring. Based on our understanding, the mirroring exercise was a medium for finding one's personal identity and paradoxically,

both facing PD and finding freedom from it. For some participants, the exercise was pleasant and emotionally touching. Others found it extremely difficult and embarrassing; initially, they struggled with this exercise. Generally, the mirroring exercise involves the imitation of movements made by another (other) participant(s) and is often used during dance classes to enhance emotional understanding, empathy, and cohesion. One theory related to the mirroring exercise is that it enhances the understanding of others' emotional intentions by exploiting mirror neuron circuitry (McGarry and Russo 2011). However, the participants' experiences also indicated that two essential parts of the exercise were the security aspect and the courage to expose oneself to others without "shields" or roles. Acceptance of one's vulnerability was also vital in the exercise, as evident in the following excerpt from the dialogue between two dancers:

> A: The mirroring was very hard for me in the beginning; I almost wanted to go home.
>
> B: Really?
>
> A: I thought it was extremely difficult. I went to the toilet when we started it.
>
> B: It was very clear when you got over it.
>
> A: Yes.
>
> B: Because you have been a completely different person in the group, it plays a major role when you find security in daring to expose yourself.
>
> A: I had a very difficult time with it in the first year. … / … It was something that hindered me before [from] exposing myself to other people, and mirrors I feel… It is a bit hard for me to explain. I felt in some way vulnerable, but I struggled and got over it, like you said, after a while. After I took on the challenge, it was very good for my self-esteem. I [had] never danced before.

Mirroring was also used in the group by merely looking at the movements of others (instead of moving with them), which might be even more personal than the actual simultaneous imitation of each movement. This also resembles the relationship with an audience while performing. According to the dancers, this form of exercise was perceived as having an impact on the quality of performance as well:

> This, when we mirror each other… It was a way to dare yourself to become open to the others (others agreeing)… When [you] sit and look at [another] for two or three minutes, you get a kind of a contact that you feel when you follow each other, and you get a warm feeling inside. That we do something together and it is good even though one doesn't perform. It becomes even stronger when you are on stage doing it. There, you kind of hear how the others are interpreting what you are expressing.

Thus, the examples related to mirroring exercises indicate how the prevailing openness and permissive personal space had become developed within the group. This led to the emergence of confidence, trust, and security within both the individual and the group. The respondents also stated that the dance teachers played a crucial role in the process (i.e., from the dance class to the performance on stage), as *they made an outstanding effort to find expressions and movements suitable for all of them with Parkinson's*. Additionally, the teachers were described as offering support to dare and inspire the participants. According to our understanding, a dance teacher can be defined

as a sort of metaphorical midwife, who allows an individual to access the art that already exists within each participant. In more detail, this was mentioned in the person's relationship, not only with dancing but also with music. For example, a dancer explained that through dancing, he/she had discovered a new language to communicate with his/her other senses:

> I listened to music before, but in a completely different way. A completely different way. It has now become some kind of a conversation.

Interestingly, in the data, the definition of performing was stretched beyond the actual space and time of a performance and was attached to other situations in their lives as well. For example, other "performative" contexts and environments, such as dancing at a party (i.e., with a crowd watching), dancing with the family (i.e., family watching), interacting and being watched by unfamiliar people, as well as being filmed and seen on TV and social media, were mentioned. Additionally, some of the dancers described how they had acquired self-assurance and self-confidence. All participants also believed that attendance in the dance classes had increased their creativity in their everyday lives. They were also able to connect their experiences of dance to their daily living, as one of them stated:

> I have realized how much it means for my health and mood to dance and move to music. If it feels a bit heavy and depressing, it can help to put on some calm music and move to it. And if you want to get a little pep and get started, you can turn on a little more poppy music. If you are stiff or frozen, the music can help. If you go out and walk, steady music in the earbuds is a support and helps to keep pace and speed up. And singing and dancing lighten up my life. I have also become more interested in watching dance and discovering how different types of music affect the body in different ways.

Discussion

In this article, our aim is to explore how dancers with PD experience dance as a performative form of the arts in the context of identity (i.e., SIT). In the analysis, we revealed two specific themes in the data. The former (Embodied social connectedness) and the latter (Leaving "Mr. Parkinson" aside) addressed factors related to social identity within the performance group and to a more personal level of the identity, respectively. To summarize, the social identity of the dancers emphasized the combined process of performing and the performance itself as a shared experience by the group. Cohesion, responsibilities, peer support, acceptance, and confidence were considered essential aspects of functioning within the group. Interestingly, their membership of the group and its social identity also enabled the dancers to develop a personal identity. In other words, the group offered enough trust and social support that allowed the dancers to discover themselves in a new way. Altogether, these findings are consistent with the results reported in the large body of published research literature on SIT (discussed earlier in the Background section). Importantly, the acquisition of a social identity within the PD dance group enabled an individual to discover an embodied personal identity that was not associated with PD but linked with artistry.

Notably, both social and personal identities were joined by the experiences of the dancers, emphasizing dance as being somehow unique since it embodied a nonverbal way of communication. This could be interpreted as a form of dialogical gaze within dance and distinguished by its importance in constructing identity (cf. Kuechenhoff 2007; Tateo 2014; Anttila, Martin, and Svendler Nielsen 2019; Houston 2019). First, for a dancer, performing is an inherent part of dancing, making the dance visible. Dancing can also be a way to explore how to become visible in a social environment, which is essential in the construction of identity. This was evident in the data. For example, the

excerpt where a participant emphasized the significance of discovering a new language of communication and its profound meaning, both while dancing and in everyday life, is proof that dance and music can be used to reveal something truly essential to the individual himself/herself and therefore important in developing a structured identity and gaining acceptance. Thus, the experience of being seen, witnessed (Frank 1995), can be empowering, building self-esteem as well as an identity (Pohjola 2018, 32), as this data confirms. Second, witnessing and watching others dancing were part of this dialogical gaze. As Houston (2019, 165) has outlined, witnessing and even attempting to embody another's movements comprise a form of communicative bodies.

In more depth, the dancers' experiences of watching and being seen could be defined as constituting an example of a communicative body, as described by the sociologist Arthur Frank (1991, 54). In the communicative body, the relationship with others and with oneself is at the same time united, dyadic, and consisting of two entities. It is not only about meeting both oneself and others but also about encountering boundaries and opportunities. According to Frank (1991, 80), this communicative body enables a two-person relationship, referring to a union that transcends the subjective body and extends into the body of the other. Thus, Frank states that a dyadic body has a sense of brotherhood/sisterhood and feels a connection to other bodies. The dyadic body perceives suffering as shared and receives assurance through storytelling and knowing that other bodies can recognize what it feels. In contrast to a dyadic body, a monadic body views itself as separate and alone (Frank 1991). In other words, as the participants watched others while dancing and were seen themselves, this enabled them to feel connected to the other dancers in the group (Bar, Czamanski-Cohen, and Federman 2021). Thus, the communicative body was formed through its relation to the others in the group. This is in line with the concept of shared corporeality, as stated by Houston (2019, 160): despite the participants being at different emotional stages in their individual journeys with PD, there may be instances – flashes – in the dance class when their bodies align, feeling their shared corporeality.

Furthermore, dance is an embodied experience and a nonverbal form of interpreting communication. Notably, it is also somatic in its nature, arising from the physicality of the body (see, e.g., Albright 1997). In particular, the kinesthetic sensations and the kinesthetic empathy that offer a psychophysical connection between the dancer's body and its viewer are significant (Foster 2011). This was one of the most important subthemes that emerged from the data; an example was the part of the group discussion about the mirroring exercise. Previously, researchers have devised a theory about mirror cells (McGarry and Russo 2011), as indicated earlier, but the act of watching dancing has also been found to activate large areas of the brain (see, e.g., Jang and Pollick 2011). Additionally, the internal simulation of movement through observation, imitation, and imagery may contribute to functional improvements for people with PD (Bek et al. 2022). It has also been suggested that during dancing, the synchronism of the intra- and inter brain between the dancers increases (Basso, Satyal, and Rugh 2021). In this case, dancing may become a shared experience, as suggested by the excerpts quoted above.

However, kinesthetic empathy (Foster 2011) remained not only as an exercise conducted in the dance studio but extended to the experience of being present at the performance and elsewhere in the individual's daily life. Thus, through dancing, the performers became in touch with one other and their audience, sharing a nonverbal interaction that while invisible, may have left long-lasting embodied traces, as one dancer suggested. According to our interpretation, the core significance of art may be one's own embodied life experiences and emotions;

this represents a deep and rich reality of meaning with a universal resonance. Indeed, dance can be interpreted as a universal language that allows oneself to connect wordlessly with others (Pohjola 2021). This is especially meaningful in identity construction with differently abled bodies. For example, the dance artist and dance researcher Adam Benjamin (2002, 6) has highlighted the importance of understanding bodily differences – how bodies work and how to feel comfortable with the possible differences that each dancer faces. Benjamin (2002, 7) has stressed the significance of improvisation, which allows a different "settlement" of the body in motion and brings freedom from predefined steps.

According to another dance scholar, Petra Kuppers (2011, 2), physically integrated dance environments are havens for many people with impairments, places where an individual can be free to explore who one is. Thus, the choices in how to act and the ideas on how to produce movement are mutually responsive. In this case, the disease or its attachment to identity is not a priority but a detachment from PD (i.e., de-medicalization). This is evident from the data. When performing, the core intention of the group is to produce art, not the pronounced visibility of a bodily injury or illness (see, e.g., Kuppers 2000, 124). Being part of the group that worked with performing offered the participants the possibility of resisting a disabled identity and emphasized social roles in negotiating identity (Sheldrake et al. 2022). This may have supported the participants' well-being, sense of self-coherence, and self-value (Wieringa, Dale, and Eccles 2022). This relates to Frank's (1995) concept of post-colonialism, where the idea of a person breaking free from medical colonization (i.e., medicalization) enables the individual to regain one's own voice with regard to one's illness. This is also in line with previous research stating that the possible hallmark of PD does not define the individual; instead, the participant is above all a person, a dancer (Butt 2017).

As far as we know, this is the first study to describe the experiences of dancers with PD in the context of performative dance. Several limitations should be mentioned. First, in general, this study offers a narrow and personalized view of some actual phenomena; in other words, the findings cannot be generalized. Second, linguistic problems may be encountered in a discussion or an interview with a person who may experience challenges in cognitive functions due to PD (e.g., Aarsland et al. 2017; Houston 2019, 26). In fact, this challenge was taken into account by using two different ways to collect the data in order to ensure that all participants had the possibility to take part in the study. They could respond by filling in the online survey questionnaire (they were able to seek assistance if needed) and/or joining the discussion group. It should also be considered that the data consists of an interpersonally constructed discussion, which may have hindered the expression of more personal reflections and experiences. Nonetheless, it is noteworthy that the focus group discussion enabled both personal and group experiences to be shared, which is one strength of the study design. For instance, when one participant started having difficulties with speech or got tired in the middle of a sentence, there was always someone in the group who gently finished the sentence or created a breathing space for the other person to continue later. Lastly, research bias is possible in the current study, as the participants may have had previous positive experiences of dancing in a group. Therefore, we suggest that in future studies, a larger number of participants would be beneficial. Furthermore, as the participants implicitly referred to the traditional association with possibly negative connotations of PD, we recommend that this important topic be further researched.

Conclusion

The social identity of the dancers emphasized their group spirit and responsibility for one another; they created a performance together, and everyone in the group became important – no matter how little or how much one participated. The experienced embodied social connectedness, peer support, and trust also enabled each dancer to explore and negotiate a personal identity that was not associated with PD. This allowed the individual to grow and learn something new about oneself and others. Significantly, this de-medicalized the dancers as well. Moreover, according to the experiences of the dancers, artistry has no bounds or limitations. Even if the physical body is limited, artistry can still be reached beyond physicality. Dancing offered the individual the possibility to be part of a communicative body and to have faith in daring to open oneself and be seen. Here is my body; here is my movement – here I am. Importantly, PD was set aside; what prevailed was only dancing, a universal language that connects human beings.

The small number of participants limits the conclusions that can be drawn from our findings; thus, they must be considered preliminary. Nevertheless, our findings imply that dance as a performative art form may be a feasible way to support group membership in a unique manner, which also enhances the creation of a personal identity. In the future, studies with a larger number of participants would be beneficial.

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ÅÅ and HP (questionnaire) and ES (discussion) collected the data. HP conducted the data analysis. All authors co-wrote and contributed to the article and approved the submitted version. All authors declare no potential conflict of interest.

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Table and figure

Table 1.

Semi-structured questionnaire (submitted online).

Closed questions:

1. How long have you been dancing in the Dance for Parkinson's group?
2. Do you participate in online classes, dance studio-based classes, or both?
3. How old are you?
4. How many times a week do you dance (at home and in the group)?
5. If you dance at home, what have you learned during the dance classes? (possible comments)
6. Do you feel that the dance classes have affected your creativity in your everyday life? (possible comments)

Open questions:

1. Why do you dance? What does dance mean to you?
2. How does it feel to rehearse a dance choreography (that you know you will perform)?
3. What does it mean for you to perform?
4. For you, what is the difference between dancing in a regular Parkinson's dance class and having a dance class with a focus on creating a dance choreography that will be a performance?
5. What force drives (what motivates you) to perform in dance?
6. In your view, why does the dance teacher's role entail involvement in the entire process from the dance class to the stage performance?
7. What did you think was the most meaningful aspect for you when you created and performed the dance choreography?

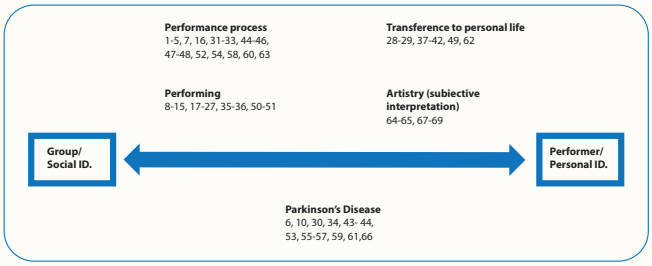


Figure 1. Subthemes emerging (and related numeric coding) from a group discussion analysis (in relation to the theoretical framework, social identity theory, SIT).

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