Escape, expand, embrace: the transformational lived experience of rediscovering the self and the other while dancing with Parkinson's or Multiple Sclerosis

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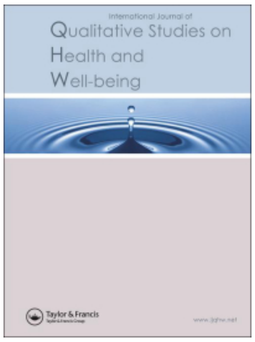

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EMPIRICAL STUDIES

Escape, expand, embrace: the transformational lived experience of rediscovering the self and the other while dancing with Parkinson's or Multiple Sclerosis

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ABSTRACT

Purpose: The purpose of this study was to explore the lived experience of dancing with Parkinson's and Multiple Sclerosis in an inclusive dance group called ReDiscoverMe (RDM).

Methods: Participatory research approaches and interpretative phenomenological analysis were used to make sense of the lived experience captured in interviews and observations. Arthur Frank's conceptual framework on embodied storytelling from his book *The Wounded Storyteller* was the study's theoretical lens. Themes are both described and represented in images made by an RDM participant.

Findings: Dancing in a nonjudgmental environment was described by participants as a way to rediscover themselves while continually adapting to living with chronic illness. We interpreted this experience of rediscovery as an active, recursive process involving three "movements": escaping, expanding, and embracing. Through these movements, participants could rise above the self and illness.

Conclusions: The lived experience of dancing in this group was characterized by transformations of the body, self, and life. Through escaping, expanding, and embracing, participants could more easily embrace the body's contingency, integrate the self and body by becoming dancers, connect with others living with illness, and produce desire through passion. Participants could therefore experience illness as a journey and gain something from the experience.

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Parkinson's disease; Multiple Sclerosis; participatory health research; dance; inclusive dance; chronic illness; lived experience

Introduction

> 'I was a little bit lost in where I was and finding myself, and then dance came into the picture. And that was like a magical key.' (Christine, MS)

> 'In dance, Parkinson's is no longer an enemy. I rise above myself.' (Hannie, Parkinson's)

Given its potential for health promotion, there has been growing interest in dance as a therapeutic tool for people living with chronic health conditions (Kiepe et al., 2012). There has been particular interest in dance and Parkinson's, a neurodegenerative condition that can lead to increasing physical disability and complex psychosocial challenges. While most research has aimed to measure dance's impact on clinical outcomes relevant to Parkinson's, there is growing interest in understanding the experience of dancing from the person's perspective through qualitative approaches (McGill et al., 2014).

Findings thus far have revealed that participation in tango can be experienced as leading to improved physical ability and control, increased participation in daily activities, and the transference of movement skills from class to daily life (Holmes & Hackney, 2017). Tango has also been linked to improved body awareness and control, which have been proposed to improve mobility and quality of life (QOL; Beerenbrock et al., 2020). Dance may also lead to the regaining of identity through self-management of Parkinson's and decrease isolation through socialization (Bognar et al., 2017). The experience of dance has also been described as supporting people living with Parkinson's to feel beautiful and find freedom from stigma, disease, and movement limitations (Houston, 2019).

In contrast to Parkinson's, there has been far less research investigating dance and other neurological conditions, such as Multiple Sclerosis (MS; Patterson et al., 2018), a chronic, unpredictable and often progressive neurological immune disease. Researchers

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have begun to apply the lessons learned in dance and Parkinson's in this context (Sonke et al., 2020). The few studies investigating MS and dance show promising results, yet have similarly focused on clinical outcomes, such as ataxia (Scheidler et al., 2018), balance (Mandelbaum et al., 2016), and disability status (Ng et al., 2019). Only one investigation, a case study involving a single person, emphasized the expressive side of dance and included the participant's perspective (Salgado & de Paula Vasconcelos, 2010). The participant described improved self-esteem and feeling "more cheerful, happier, and like somebody," which was "very important."

Dance as a tool or instrument has the potential to influence physical, emotional, social, and spiritual aspects of life (Quiroga Murcia et al., 2010), yet there continues to be a lack of research that explores these characteristics of dance in health contexts holistically and dance's *intrinsic* (versus instrumental) value and meaning, as expressed above by Christine and Hannie. One way to study the lived experience of dance for people living with chronic illnesses is through Participatory Action Research (PAR) in which knowledge is co-produced with those it concerns (Phillips et al., 2021). PAR is useful for developing understandings of complex, ambiguous phenomena that are hard to measure (T.A.S. Abma et al., 2019, p. 158). It also has the potential to counter "epistemic injustice" (Fricker, 2007) and lead to better understandings and improvements of people's life worlds by maximizing participation of those whose lives are at stake (T.A.S. Abma et al., 2019, p. 8). Moreover, participatory approaches work synergistically with health promotion by embracing the complexity of human life and its many influences, transitioning from a focus on disease and treatment to well-being and health of the whole person (Abma, 2005).

The purpose of this participatory study was to explore the lived experience of dancing with Parkinson's and MS in an inclusive dance group called ReDiscoverMe (RDM). Interpretative phenomenological analysis (IPA) was used to make sense of the lived experience captured in interviews and participant observations, and represented in images made by an RDM participant. The findings were then situated within the literature on dance and these neurological conditions and Arthur Frank's (1995) conceptual framework on embodied storytelling, which was the theoretical lens for our study. His notions on the body, described in the next section, seemed relevant to understanding dance as an embodied experience and its intrinsic meaning.

Frank's notions on the body

In his book *The Wounded Storyteller: Body, Illness and Ethics*, Frank (1995) describes the reciprocal healing power of telling illness stories. Frank's thesis is that different body types have an affinity for different types of illness narratives. These "body-selves" are created through the stories they tell, and those told about them, as well as their reactions to four problems of embodiment: control of function, body-relatedness (the association of the body and self), other-relatedness (relationships with other bodies), and desire.

Frank proposes that all body-selves face these four problems and that they are heightened during illness. Each problem is a problem of action to which the body-self may respond in a range of possible ways. Body control exists on a continuum opposite contingency, or "the body's condition of being subject to forces that cannot be controlled" (Frank, 1995, p. 31). Loss of control becomes a significant problem in Parkinson's and MS due to day-to-day unpredictability of the body's capabilities and uncertainty surrounding its future (Bramley & Eatough, 2005; Giovannetti et al., 2017; Haahr et al., 2011; Wilkinson & Das Nair, 2013). Body-relatedness is the tension between seeing one's body as one's own or as a "thing," which may change in Parkinson's or MS due to a disturbance of an integrated body-self unity (Bramley & Eatough, 2005; Toombs, 1992). Other-relatedness determines whether one sees oneself as existing alone or with/for others through, for example, increasing social isolation on one end of the continuum or becoming a patient advocate on the other. Desire, the quality of wanting more for, with, and through the body, may be productive or completely lacking. Frank suggests desire is invariably lost at some point in illness; at its most extreme this might mean loss of desire to live.

Frank then proposes that the ways in which ill people respond to these problems yield four body types: the disciplined body (defined by self-control), mirroring body (defined by consumption), dominating body (defined by force), and communicative body (defined by empathy). These are not mutually exclusive or exhaustive. The communicative body, he believes, distinguishes itself by being the ethical ideal of the four. It is idealized because it accepts the body's contingency, understands that the body and self exist in unity, empathizes with other suffering bodies, and produces desire, often by finding purpose in illness. People living in such a body-self can thus more easily accept or adapt to living with illness.

Frank (1995) also proposes the different body types have an affinity for one of three illness narratives: restitution, chaos, or quest. The restitution narrative focuses on the "'natural' desire to get well and stay well" (Frank, 1995, p. 78) and prioritizes symptoms, treatments, and outcomes. This plot, in which the treatment is the protagonist and bodily control is the aim, dominates published research. The chaos narrative is the polar opposite of the restitution plot in that it imagines life will never get better. These stories are difficult to hear because they are painful to listen to and because they lack coherent structure. Chaos is being "sucked into the undertow of illness" (Frank, 1995, p. 115). Finally, the quest narrative, often told by communicative bodies for others who are suffering, embraces illness as a journey and tries to find purpose and gain something from the experience. This narrative gives ill people agency as it is the only one in which the teller's voice is truly heard. Importantly, people often become different body and storyteller types throughout their illnesses, due to new complaints or perspectives.

In research exploring dance and neurological conditions, the restitution narrative has remained dominant as studies have primarily focused on the body's functionality and health-related QOL and how dance may restore these. Such focus on the effects and outcomes of dance reduces what is a complex phenomenon by missing the journey of the lived experience and the sensations experienced while participating. Moreover, this narrative may not make room for people living with Parkinson's or MS to describe the impact of dance on their embodiment and life worlds, which are likely important considerations. The symptoms and challenges those living with these conditions face can more broadly threaten self-concept and identity (Desborough et al., 2020; Rutten et al., 2021) as "the self is formed through uses of the body" (Frank, 1995, p. 180). Moreover, dance and its expressive qualities may support people living with illness to move towards becoming communicative bodies (Houston, 2019, p. 160), making the restitution narrative incongruous with the experience. Therefore, this study aimed to give voice to the dancing participants and understand their experience as testimony.

The participatory research approach

Consolidated criteria for reporting qualitative studies (COREQ) 32-item checklist was used as a guide for reporting the methods and findings (Tong et al., 2007).

Research team

This project took place in The Netherlands and was funded by a 2019–20 Netherland-America Foundation Fulbright Scholarship awarded to the first author, with the last author as supervisor. The project began with the assembly of a local mixed research team of experts-by-experience to collaborate on the study. This included a visiting PhD student (AMC), facilitators leading dance classes attended by people living with Parkinson's and/or MS (AMC, NL), people living with Parkinson's (HM) or MS (CGS) who had danced with RDM and elsewhere, and professional researchers with expertise in participatory research and qualitative methods (TAA, LT). All co-researchers were highly motivated and engaged, and all had a role in contributing labour and diverse perspectives to the project at various moments and in varying degrees of intensity (see, Table 1 for an overview of participation). The involvement of experts-by-experience was supported by a crowdfunding campaign that raised funds to cover project-related expenses and to acknowledge everyone's contributions (T. A. Abma et al., 2009). The research team became a cohesive group and shared control in decisions regarding the focus of the study, including the research questions, setting and relevant concepts, and the interpretation of the findings (T.A.S. Abma et al., 2019). Co-authorship of this article was discussed among team members, and all authors actively contributed to the writing process.

Participants

The first author participated in various dance groups in The Netherlands in Autumn 2019, and a case was selected based on its learning potential with input from various stakeholder perspectives (Abma & Stake, 2014). The original research proposal aimed to explore the lived experience of dancing with Parkinson's; however, the research question evolved to also include people living with MS after it was learned that people living with these conditions were often attending classes together in this community.

The case of focus (ReDiscoverMe—RDM) is neither a Parkinson's class and/nor MS class. It is an inclusive dance programme open to everyone with a mission of reaching people living with chronic illnesses. At the time of the study, it was primarily attended by people living with Parkinson's and MS. The idea of focusing on this case was presented to Damar Lamers, the group's founder and director in a face-to-face meeting with the first author, and then subsequently facilitators and dancers in a face-to-face group meeting where participants were introduced to members of the research team and received information about the research. In line with the holistic approach of participatory research, the artistic director, facilitators, and participants with a connection to Parkinson's or MS were invited to take part.

Ethics

The VU University Medical Center Medical Ethics Review Committee reviewed the study and determined the Medical Research Involving Human Subjects Act (Wet op Medisch Onderzoek, WMO) did not apply to this project: Niet-WMO-advies METc verklaring VUmc (2019.604). All participants provided written informed consent. Participants were given an opportunity to ask questions about the research prior to the first interview. After data collection was

Table 1. Participation matrix.

	Shaping	Generating	Sensemaking	Sharing
Anna	Writing grant proposal; formulating and developing design; conducting pilot interviews	Conducting interviews, recording observations; sharing personal experience	Formal analysis of English language data; member checking; drawing mind maps; feedback on artistic interpretation	Writing first draft of manuscript and plain language summary; dissemination
Tineke	Supervision, editing grant proposal; formulating and developing design; building team of co-researchers	Supervision, providing training materials and feedback on generated material	Supervision of analysis; drawing from extensive knowledge of relevant literature	Editing manuscript; dissemination
Rob	Partner, thinking along with design; building team of co-researchers; supporting first author network in NL	N/A	N/A	N/A
Hannie	Formulating and developing design and interview topic list	Conducting interviews, recording observations; sharing personal experience	Analysis in duo with co-researchers; generating themes and drawing mind maps	Reviewing and reacting to manuscript drafts; writing about experience; dissemination
Christine	Formulating and developing design and interview topic list	Sharing personal experience in conversation and writing	Analysis in duo with co-researchers; generating themes and reacting to mind maps	Reviewing and reacting to article drafts; writing about experience; dissemination
Natalie	Thinking along with design	Recording observations	Joining analysis discussion sessions	Editing article drafts; translation of Dutch quotes to English; dissemination
Dido	Thinking along with design	Conducting interviews	Joining analysis discussion sessions	Dissemination
Damar	N/A	Sharing personal experience; facilitating interviews and observations	Joining analysis discussion sessions	Reviewing and reacting to article drafts; dissemination
Lucia	N/A	N/A	Formal analysis of Dutch language data; member checking	Editing manuscript; dissemination
Renée	N/A	Sharing personal experience	Creation of artistic translation; discussion of themes with Anna	Reviewing and reacting to manuscript drafts; dissemination

complete, participants received a debrief with researchers' contact details and a reminder that it was possible to withdraw their data from the study.

In addition to confidentiality and informed consent, the following ethical principles were taken into consideration: participation, mutual respect, reflexivity, representation, and power (Banks & Manners, 2012). For example, participants were initially told data would be presented anonymously until one participant said she felt strongly that her name be used in connection to her story. All participants were subsequently given the option of being credited for their insights or using a meaningful pseudonym. This is in line with other qualitative work on dance in health contexts (Houston, 2019; Phillips et al., 2021). Given the implications of naming some participants and not others, consent was again sought for use of all quotes and observations included in this report, and those who chose to use their own names provided written consent to publish.

Data collection

The lived experience of dancing was captured through observations and semi-structured interviews (see, Table 2).

Table 2. Quantitative details of data collection.

Observer hours logged	
Anna M. Carapellotti	78 h
Hannie (J.E.M.) Meijerink	20.5 h
Observation settings	RDM dance classes RDM rehearsals Inclusive dance festival Dance and health themed symposia Other local dance classes
Interview 1 settings	Home (n = 4) Dance academy (n = 6) The performance theatre (n = 2) Private room at university (n = 1)
Interview 2 settings	Home (n = 1) Dance academy (n = 2) A café (n = 1) On the phone (n = 3)
Interview 1 duration *M* [range]{total}	1h8m21s [32m36s—3h28m23s] {15h56m28}
Interview 2 duration *M* [range] {total}	48m32s [20m54s—1h21m07s] {5h39m6s}

Observations

Participant and non-participant observations were recorded in a notebook during or immediately after classes and rehearsals and then digitally transcribed. Dimensions observed included the space, actors, inter-relational dynamics, movement, feeling, music, aims, and changes over time. Participant observations and informal conversations allowed the researchers to gain a broader understanding of the dance classes and those taking them, as well as the opportunity to explore their own inner feelings while dancing with the group. Non-participant observations taken while watching rehearsals and classes as a "fly on the wall" allowed for a more distanced position and factual observations.

Interviews

Interviews were semi-structured with the research team contributing to the topic list and ideas developing from observations. All were female novice interviewers who received training materials. The semi-structured nature of the interviews led to broad questions about the experience of living with Parkinson's or MS and of dancing. Follow up questions used wording chosen by participants themselves and encouraged them to elaborate or explain more. Interviews took place at a location chosen by participants, were audio-recorded, transcribed verbatim, and anonymized. The founder/director and participants were interviewed twice, before and after a dance festival in which some group members performed. Facilitators and one participant who did not take part in the performance were interviewed once.

The interpretation of findings

Data were analysed using IPA following the approach outlined by Smith et al. (2009). This process involved reading and rereading interview transcripts, observations, and notes from discussions with researchers, participants, and other stakeholders. Initial notes, including descriptive, linguistic, and conceptual comments, were made in a column on the left-hand side of transcripts and observations in Microsoft Word. The coding of emergent themes was then done on the right-hand side. Reactions to transcripts, observations, and themes were also recorded in written reflections and verbal reports to maximize participation (T.A.S. Abma et al., 2019, p. 161). Connections across themes and cases crystalized through discussions with researchers and participants, personal reflections, mind map drawings, the reading of relevant texts, and the writing process. Mind maps (e.g., Figure 1) resulted from, as well as inspired, the research team's discussions of the findings and became a part of the interpretative process.

Themes were derived from the data with an aim to give voice to concerns of participants and make sense of the experience of dancing. The study focuses on the experiences of those living with Parkinson's or MS, while the others interviewed (e.g., facilitators) provided valuable contextual information that aided a deeper understanding of dancing with RDM. In line with recommendations for conducting IPA with homogeneous samples (Smith et al., 2009, p. 49), we began the analysis by focusing first on dancers living with Parkinson's then MS to keep open the possibility of disease-oriented themes emerging and a need to compare experiences. The findings were ultimately presented holistically as the overarching impact of dance for participants was consistent across cases.

The double hermeneutic required in IPA, in which the researchers are making sense of participants who are themselves making sense of an experience (Smith et al., 2009, p. 35), was

Figure 1. *Hannie's mind map of "rise above the self"*: A big bowl filled with fluid representing reality/daily life. The magical world of dance is the heater, the energy source, the fire that heats the big bowl. The warmer the fluid gets, the more gassy bubbles appear (the key elements of dance). They get higher and higher in the pot as the temperature increases. When it's optimally hot, the bubbles escape on the upper side as steam: the rise above yourself. All the elements in the pot move around constantly. When there is no energy from the magical world, the fluid will be cold and thick without any bubbles. If there is too much heat, the pot can boil over.

strengthened by having a mixed team discussing the interpretation: people living with and without MS and Parkinson’s and having and having not experienced the phenomenon under investigation. More than one year was taken to complete the analysis to provide adequate time for themes to evolve and core beliefs and assumptions to be unsettled and considered.

All participants received a summary of their interviews (individual member check) and a subset received a summary of the findings (group member check) to confirm the accuracy of the interpretations and to enhance credibility. This process often resulted in follow-up conversations that led to clarifications or further insights. Confidence in the analysis was strengthened when researchers and participants alike recognized their personal experiences in the findings.

Translation of themes

Throughout the writing process, Clifford Geertz’s (1973) notion of “thick description” was used to ensure the text would affect readers to “vicariously experience” dancing with Parkinson’s or MS and help them generalize the findings of this study to their own contexts (Abma & Stake, 2014). In the first part of the Findings section, *Context*, the participants and RDM dance classes are described in great detail to ensure a holistic understanding of the group and its subtleties (Simons, 2015). In the following section, *The transformational lived experience of rediscovering the self and the other*, written descriptions of three themes depict the meaning of dance to these participants. Each theme is followed by a reflection that connects this aspect of the experience to Frank’s (1995) theory on embodied storytelling, and a concluding paragraph outlines how and why all of the themes exist together as a part of a recursive process. The integration of the three themes is illustrated further through the detailed experiences of two researchers and RDM participants, Hannie Meijerink and Christine Gravemaker-Scott, shared in the form of a poem and a reflexive journal entry, respectively.

Additionally, the lived experience is interpreted visually in images made by Renée Kool, an RDM participant and professional artist. Images are included to convey the sensations of dancing and its impact that cannot easily be put into words (e.g., the “magic” of dance, expression through movement). Mind maps and manuscript drafts were shared with Renée for inspiration, and she made collages of performative hands to represent the lived experience. She chose to use images of hands cut from free publicity magazines to represent the dancers because such hands can express visually, and metaphorically, the complexity of bodies moving in relation to each other and the depth of the lived experience. Anna and Renée met regularly for conceptual exchanges and eventually selected from a collection the images that represented visual associations of the themes outlined in the Findings section and their intersections.

Findings

Context

Participants

Thirteen people agreed to participate in this study, and one agreed to participate then could not be reached for an interview. One was the founder of RDM, three were facilitators, and nine were participants. The founder, Damar, a professional dance educator, developed “ReDiscoverMe” after finding dance to be a way to rediscover herself after her MS diagnosis “*because everything in my body worked differently*.” The classes were led by two facilitators, Mike and Noëlla. They always led the classes together, with Noëlla (an intern) gaining more responsibility during the months observed. The third facilitator, Maxi, also a professional dancer and educator, led rehearsals in collaboration with Damar. Facilitators ranged in age from 25 to 55.

The dancers interviewed ranged in age from 28 to 70 and included three people living with Parkinson’s, three people living with Relapse and Remitting MS, two people living with Primary Progressive MS, and the son of a woman living with MS (not a dancer in the programme). Participants living with MS or Parkinson’s were all diagnosed prior to age 55. All were forced to stop working completely or reduce responsibilities earlier than desired due to increasing changes and uncertainty surrounding bodily capabilities. Many had worked in creative fields or had studied art. All described dancing (or dreaming of dancing) in some capacity during their lives. The majority began dancing with other community dance groups for people living with Parkinson’s or MS prior to joining RDM and were also dancing at other classes at the time of this study. All lived independently or with a partner or spouse and all attended dance classes independently, not with other family members. Three living with MS were observed using assistive walking devices (sticks and a rollator), though not always during class time. Though this study focused on participants of RDM, the findings describe their dance journeys holistically.

The transformational experience of MS or Parkinson’s before dance

Though the participants were living with different diseases or disease subtypes, their transformational experiences of illness, as they related to the transformational experience of dancing, were characterized by many similarities. The onset of illness for all participants, which for many came years before a diagnosis, led to many losses including careers, physical mobility, travel, active lives, relationships, aspects of independence, self-esteem, and confidence. This led to feelings of life getting smaller: "*everything became less*." The fast-paced world was also confronting while being forced to slow down due to a changing body, as was the judgement of strangers some began to experience in the form of "pitiful looks" or "deadly gazes." Some wondered if they wanted to continue to live with such a condition, considering suicide or euthanasia. With such losses, acceptance of illness was challenging and scary, especially given its permanence, unpredictability, and complexity. Participants described fearing the future and finding it confronting to be around people in more advanced stages of these conditions. Many avoided MS or Parkinson's activities, such as "cafés" (i.e., support groups), because they were not ready to deal with this confrontation or because they did not want to identify with illness. Participants found that inclusive dance programmes like RDM could offer them something different from such support groups.

Ideology of facilitators

Damar developed RDM with the goal of creating a dance space that empowers and integrates people living with and without chronic conditions. She believes that by working together on the dance floor everyone can rediscover *"we are just human."* The facilitators also aimed to empower others through dance and believed dance should be for everyone, not just professionals or those with "perfect" bodies.

To create an empowering, inclusive dance space, empathy, equality, safety, and communication were described as important by facilitators and participants. Damar believes empathy, next to dancing ability, is the most important skill for inclusive dance facilitators; this ensures participants are not victimized. To achieve a spirit of equality, a pillar of RDM is to work without hierarchy. Classes and rehearsals were almost always led by more than one facilitator, and facilitators often participated as dancers. Dancers living without chronic illness were not invited as "volunteers" as is common in classes for people living with neurological conditions; they joined as fellow dancers. Empathy and equality created a nonjudgmental environment where dancers could feel emotionally and physically safe. When considering "safety" in dance for people living with disabilities, the emphasis is often on preventing falls and injuries; however, not giving dancers space to take risks or trust themselves seemed equally harmful. Facilitators also emphasized the importance of learning how each individual communicates with words and their bodies. Communication through movement was described as "powerful" and "magical," contributing to the nonjudgmental culture by making words both unnecessary and inadequate. The stimulating, artistic environment of the theatre and dance academy where classes were held made everyone involved feel like a part of a community of dancers, which contributed to the inclusive atmosphere.

Experiencing movement and improvisation in RDM

RDM aims to transcend being for one type of body, with the solution to this being to transcend dance styles. With an emphasis on improvisation, a practice in which participants generate their own movements with guidance from facilitators, space is created for everyone to continually discover for themselves how they can and want to move.

RDM classes begin in a seated circle to establish equality and connectivity among facilitators and participants. Dancers are invited to first turn their focus inward to generate energy for themselves and tune into how their bodies feel today. Gradually throughout the class, the body and its movements build up, and one gets the sense when observing and participating that the room is gradually becoming more and more alive. The movement expands, starting from small undulations of the core and eventually to the extension of extremities. Led by the music, participants reach further and explore more movement qualities with time. The facilitators were observed to be positive and relaxed, never commenting if someone did the "wrong" thing. After generating energy for the self, facilitators invite participants to share this energy and build connections through eye contact and synchronized gestures.

> *Anna fieldnotes: After about 25 minutes into class, the group is instructed to move in synchrony for the first time. Arms float up and arms float down. Scooping towards the body with the arms, rocking back in the chair with an inhale, some feet float off the floor. Pushing forward with the arms, exhale, make eye contact with someone across the room. Eye brows raise, people smile, twinkles in the eyes. Mike introduces circular movements. Rolling the shoulders and drawing circles on the floor with the feet. The dancers are instructed to allow the movement to come from one hand. Reaching in all directions many begin to explore the space behind them. "Moooooiiii" ['Beeeauuutiful!'] Mike encourages and compliments. Now the movement is initiated from various parts of the body: head, shoulder, knee. People are moving at various amplitudes, suggesting that everyone is feeling comfortable moving in their own range. [...] A new dynamic: Fast! The dancers make wild, fast movements with their hands and arms followed by a pose in stillness.*

The final part of class involved contact improvisation with a partner or small group. This involved exercises like exploring the negative space around one's partner(s) (tracing around their body without touching it), mirroring each other's movements, or physically responding to the touch of another. Many participants described this part of class as taking time to become comfortable with, as it involved being very intimate with others and vulnerable in the movement creation process. Connections built through being greeted with a hug and sharing energy earlier in the class helped develop an atmosphere for closer physical and emotional contact. Sometimes participants were invited to watch each other do these exercises. Afterwards, there was an opportunity for participants to reflect and describe "how it was for them" or what they observed or felt in others.

> *Hannie fieldnotes: We do an exercise in pairs. One is standing in a comfortable position, stable. The partner explores the resistance and strength in that pose. How much can he/she push without bringing the other in disbalance. We have to trust our partner in this situation. That you can lean on him or her without falling. The group is more comfortable in this than me. I find it difficult to respond to my partner with my eyes open. I think too much then, when I close my eyes I respond more instinctively. The group recognizes this as a starter's thing. In time, they say, reactions become more automatic.*

After the class (lasting 1.25 hours), all but one participant stayed for an additional couple of hours for a rehearsal of a 10-minute performance piece for an inclusive dance festival. The one who did not stay described not being interested in performing and finding the length of the day "too much" due to her experience of MS. Two participants ultimately did not participate in the performance due to an injury and stroke, respectively. The piece involved two duets and several ensemble sections, all of which involved improvisation within varying degrees of structure. Damar described this piece as a "trailer," a small step towards a full-length production where the group can share their stories on stage.

The transformational lived experience of rediscovering the self and the other

Like Damar, RDM participants, in their own ways, described dance as a way to rediscover themselves. We have interpreted this experience of rediscovery as an active, recursive process that involves three "movements": escaping, expanding, and embracing (Figures 2, 3, 4). Through these movements, transformations of beliefs about and experiences of the body, self, and life could occur, in some cases from the very first dance class (Box 1).

Box 1. A poem written by Hannie (J.E.M.) Meijerink after her first dance class with Parkinson's.

My unforgettable meeting with Dance for Health

Eyes that welcome me. Immediately I feel comfortable with these people.
A little chat and when the music starts, concentration.
Like a spiderweb, a flow of positive energy arises between Andrew and dancers.
You feel the intention to enjoy this hour in this class.
Attention and empathy for each other. Taking someone's hand to help getting started or an encouraging look.
But most of all the realization that Parkinson's is not the unwanted and unloved intruder in this place.
This morning he does not decide what you can or cannot do.
Together you are beautiful by moving to music.
Rediscovering strength and balance, both feet firmly on the ground.
A class that teaches you something valuable: love your body and cherish it the way it is.
Be proud of it and let it go in this dance to music.
Let your muscles explore and become aware how they can move in a dance.
Let them experience how much more they can do because you want to make it happen. And you let it happen.
Feel how your way of moving activates all that flows in your body.
Experience how love and attention for your body, and all the things it can do, makes your movements better and lighter.
Emotions, emotions, I feel so good!
The flow I get into, by moving to the rhythm of the music, makes me happy.
For me there's no better medicine than music and dance.
I totally agree with Andrew, who wrote this:
More people should feel their body's.
The Parkinson's party should be open for all.
Thanks, it was great, I am happy!

Translated from Dutch by Hannie and Natalie Lewin. "Dance for Health" was a Dutch organization offering classes for Parkinson's, MS, & Rheumatoid arthritis from 2013 to 2019. "Andrew" was the facilitator on this day Hannie first attended.

Escape: rise above the self to experience freedom from disease and its limitations

Dancing in a nonjudgmental environment created space for participants to "rise above the self," where they could transcend to another level of being (Figure 1). This offered an escape from disabilities, barriers, and problems where participants could let go of unwanted identities, negative stress, and limitations. Hannie describes this experience for her:

> *It is rising above daily life with limitations and escaping from disabilities. But it is also rising above the self, and getting in the flow, into something special that you don't experience doing other things. It feels lighter than normal, as if you are a little drunk. Everything is possible then, you don't know where the dance and the music will bring you. That's a big surprise every time you dance. Like Alice in Wonderland. Yes, I feel like another person when I dance. The sky is the limit.*

In this state, participants could let go of assumptions about themselves and no longer had to question whether how they were moving was "right" or good. The first experience of this escape was described as "overwhelming," "empowering," or "liberating." There was an immediate intuition that dance was good for the body and spirit and a desire to experience more of it.

> *Lucy: Until then, I had only, I had been going to classes that were called MS um Groups, in the physical therapy practice, and we would practice certain things to music sometimes but it was often dun, dun [marching in chair] and all of a sudden it was this [reaches arms in graceful sweep] and this [more sweeping gestures] [laughs] and I just … it was air under my wings, I mean, it was just so empowering.*

The transcending experience of dance was thus characterized by freedom of movement and expression. In such a state participants could "let it go" and "not think," while paradoxically feeling more in control; this was supported by the music and experienced as a flow-like state in which participants could take risks and move in ways that surpassed real or imagined limitations.

> *Charley: I make movements and then afterwards I think, Did I do that? Wow! I didn't know I could do that! That I'm so into the movement and the, the thing we are creating or doing that I forget that maybe I shouldn't be doing this wild jump […] I forget my limitations or even imagined limitations maybe.*

To be free to move without judgment or fear when living with a condition that affects movement was empowering on its own and this was enhanced through positive feedback and encouragement from facilitators and other dancers. Participants described feeling like they were being given permission to move and discover with their bodies whereas in other situations they felt they were being told what they could or should not do because of their illnesses.

> *Christine: It was as if you were opening a box or a room or whatever and just finding all these wonderful things within that room, which after years of being told you can't do this [scolding sounds].*

Some found this freedom easily through improvisation, while others felt they could move more freely when following a leader or improvising within more structure. These differences sometimes resulted in tensions as people described wanting to dance in ways that allowed them to optimally experience freedom. Freedom of movement discovered while dancing also led to freedom in reality, giving participants the confidence, determination, and tools to keep moving through life despite physical struggles.

> *Lucy: The dance has really just opened my eyes to so many things. Just freedom of movement is, is, is incredible [laughs].*
>
> *Anna: Now I want to ask you why it is incredible!*
>
> *Lucy: Because most people who have a [limitation] syndrome spend most of their time in a chair, and they don't, and they get up like this and ugh [moaning], you know, it's just a struggle and older people don't even want to have to go, they don't drink enough because they don't want to have to get up and go to the bathroom and that's just horrible to get to that stage. You need to keep moving and that freedom is just part of what you get from dance.*

Dance also provided freedom from illness through being an energy source. Fatigue was described by participants as one of the greatest restrictions of living with Parkinson's and MS. Importantly, dance gave participants the tools needed to manage fatigue so that they could have the energy to keep moving and rediscover themselves.

> *Renée: If we have done the class first and then we do our rehearsal for the piece so that's about two and half, three hours, of quite intense movement, I'm very tired, but I find, and this may sound totally crazy, I find myself Parkinson's free. It feels as if I'm my normal self. And that is the best experience of course. It's amazing. That doesn't last very long but it is there, and that is a crazy feeling. Yeah.*
>
> *Anna: Can you describe for me what it feels like to be Parkinson's free?*
>
> *Renée: […] When I walk out of theatre school, I'm tired, but I don't feel the things I'm describing to you now, I don't feel the stiffness, I don't feel that my left side is different from my right side, I don't feel the need, sometimes I'm tired but I don't feel the need to go to bed […] The moment I walk out of there my brain is my own normal brain, my artistic brain where I'm always thinking about things, making interconnections, seeing things, thinking about new ideas, new projects, computing other things, [inhale] it's amazing.*

Freedom from disease was thus not experienced as a cure, but as a feeling of liveness and a rediscovered frame of mind. There was not a one-size-fits-all approach to accessing this frame of mind with some participants discovering they needed to dance more and others less to find the optimum intensity for transformation. This was the only minor theme that seemed disease-oriented: people living with Parkinson's discovered that with more dance that they could gain more energy and freedom, and people living with MS described the importance of learning their energy limits in life and dance.

Connecting Frank's (1995) notions on the body

The rise above the self is characterized by an escape in which the body and self can integrate in an altered state of consciousness. This escape created a paradoxical feeling of letting go and gaining control. The encouraging way in which the dancers were treated by facilitators and the energy generated through dance influenced their ability to access this state; this was in contrast to feeling limited or restrained by illness in other situations. Participants wanted to experience more freedom of movement in dance and in life, which cultivated desire.

Expand: rediscover possibilities for the body, self, and life through the dance community

Dancing offered the freedom, energy, and confidence needed to expand the self through (re)discovering

Figure 2. Escape, expand, embrace (1) by Renée Kool

identities. Physical challenges and the shock of a diagnosis led many participants to feel like they were "going downhill;" many losses (e.g., careers, energy, relationships) led to feelings of life getting smaller. Dance in contrast presented an exciting opportunity and a community that promoted possibilities and a positive outlook. Christine described her first experience of dancing with MS as a "magical key" that "turned her life around":

> *My outlook changed very quickly from being one of kind of, uhh, kind of negative, you know, not kind of caring, not that I wasn't caring anymore, but just like thinking, okay, this is it [groaning] it was just suddenly like now there's a whole new world out there to be explored.*

Dance helped participants explore possibilities for both the body and self, which was a relief. Participants expressed desire to dance more and "better" by learning to move more freely or express themselves in new ways. Several participants described joining RDM, which emphasizes creative development as opposed to dancing for health, out of a desire to dance in a more artistically intense environment. Several participants also very quickly had a feeling that dance could become their "new area" or "passion," which produced desire. Desire was also cultivated through fantasy, and music supported this process by helping participants to reach further and embody new qualities.

> *Peter: Truly a relief, playing with your body and starting to think a little bit that you lost it when you haven't lost it at all. That you could keep renewing your own feelings, explore them. Put your fantasies in there a bit, thinking you are an amazing star dancer.*

An emphasis on freedom and expression meant that even with increasing movement challenges, it was still possible to find new ways of moving in dance, whereas in other, even disease-oriented, activities new challenges possibly meant exclusion.

> *Jeffery: Dance you kind of use your whole body the whole time. So and the hockey [for people with MS], to be honest I just stopped doing hockey, because uh I noticed I wasn't, I can't really run anymore, and that's, I thought that was a shame, with hockey, if you can't run, you can only walk, even the walking isn't going very well. Um, but dance is more like you move your whole body, and yoga and hockey, that's limited.*

Importantly, moving freely was also simply "fun," which was associated with youthful feelings of open-mindedness, discovery, and growth. This also felt similar to the experience of travelling, something many participants could no longer do and greatly missed.

> *Charley: I'm just looking for different ways of travelling and I'm learning very much so that it doesn't mean you literally have to go very far, and I think dancing is one way of doing that.*
>
> *Anna: Hm. How does dancing feel like travelling?*
>
> *Charley: Um… Yeah, I guess to some extent when I travel, especially when I travel abroad, it's being somewhere new, somewhere different, somewhere stimulating, where they have different food, different language, and I'm part of it and really indulge in it, um, the dancing is like travelling within my own body, kind of, the possibilities of my movements and the movements of others and your, especially when you're improvising it's like being on a journey together, really, and the fun is you start this journey, and you don't even know where it goes, and that's the exciting, the exciting thing about it.*

The dance journey also led to personal growth. Dancers observed in each other the development of confidence and trust through the creative process and were vocal about their admiration for each other. Facilitators also observed participants going out of comfort zones physically and emotionally, and their encouragement cultivated further growth. Importantly, the transcending nature of improvisation gave participants the freedom and responsibility of discovering their own "top" as dancers in the same space; however, with so many different abilities in the room, it was sometimes confronting to see others reaching a top that might never be attained.

Opportunities for expansion also extended beyond classes as dance became a new community to which to belong and contribute. Supporting this community was a chance to rediscover talents and interests and to develop new ones through becoming involved in the creative process. It was also an opportunity to contribute to the expansion of the community itself so that others could experience its transformative power. This led to being a part of something bigger than the self: the larger cause of sharing the magic of dance. Participants and facilitators alike felt a desire and responsibility to show the world that dance is for everyone and how powerful it can be. They also wanted to show what is possible for a person living with illness, having been given hope by witnessing the positive experiences of others.

Dance also became something new to discuss with friends and family, which was meaningful because some participants felt prior to this the topic of conversation had focused on their illnesses. Dance could thus lead to becoming a multidimensional and whole person again in one's own view and in the view of others, with the many puzzle pieces of participants' identities coming together in this context.

Connecting Frank's (1995) notions on the body

Expanding the self gave participants control through agency, shifting them from an uncontrollable feeling of going downhill to actively growing through dance. The transcending nature of improvisation could provide seemingly endless expressive movement possibilities, and this creative growth led to personal growth. Dance also became a new way to exist with and for others through supporting the community, sharing experiences, and inspiring others living with illness. These expansions further integrated the body and self and again led to a desire to dance more.

Figure 3. Escape, expand, embrace (2) by Renée Kool

Embrace: accept, enjoy, and trust the body-self and that of others

Through dancing in a non-judgemental environment, participants were able to embrace their whole body-selves, including limitations and vulnerabilities. This did not necessarily mean accepting illness; participants rather described adapting or flowing with its challenges, no longer rejecting their body-selves, and embracing the opportunity to gain something from the experience. The embrace of the self was influenced by the embrace of others in the supportive, accepting, and enjoyable dance community.

Dance was described as a way to connect with illness and others living with it that is not *"negative downward gloom."* Participants described avoiding MS or Parkinson's cafés because they were depressing or not interesting; dance conversely allowed participants to engage with their bodies and others in a more light-hearted and enjoyable way. Participants discovered the value of spending time with other people who shared the experience of illness so they could exchange knowledge and support, and appreciated circumstances that facilitated getting to know each other on a deeper level. Together, participants also discovered the body is still something to find pleasure in and have fun with, rather than just a struggle. Participants also supported each other directly during contact improvisation. Dancing in this way involved keeping each other on balance, physically touching, and being vulnerable in the movement creation process, which required building trust. This allowed participants to do things together that they might not have been able to do alone.

> *Anna fieldnotes: We did the exercise that involved testing your partner's limits of stability through pushing, pulling, and giving weight. Jeffery pushed against my arms, the outsides of my legs, my shoulders from behind. A couple of times I lost my footing a bit and had to brace myself and take a few steps. He commented, "You're strong!" After that, I felt him increase the amount of weight he was sharing with me, draping himself over my shoulders, or resting on my back like a tabletop, both of us bent forward at the waist.*

Through learning to trust and being trusted, dancers began to trust their own bodies. Eventually, some dancers described actively giving trust to another. Coming to trust and understand the body was a way of taking control and learning to manage one's own body; however, this sometimes meant letting go of control and accepting support, and learning that allowing the self to do so is really a strength. This culture of support was observed in diverse ways in the studio:

> *Hannie fieldnotes: What struck me: Strong social mutual involvement and care. Renée is a strong observer and has an eye for that. She helped Jeffery and Theresia, saw that*

> *during the dance it went too fast for Christine. She will immediately mention this. Charley approached Theresia repeatedly during class to translate when English was spoken. Had bought shirts for everyone [for the performance] at Zeeman. The group is also open: I am new to most, but already feel very much at home in the group, being accepted as one of them.*

In contrast, in the outside world, participants described experiences of rejection and feeling the need to protect themselves. It was a challenge to "stay human" with such changes to the body and judgement in the form of "deadly gazes" and "pitiful looks" from strangers. In an inclusive dance space, participants felt they could simply be themselves without being judged. Theresia described her experience of meeting people living without disabilities at RDM classes compared to jazz ballet classes or the gym:

> *Theresia: [There] you are confronted with people who are still ehm… normal, ehm… now too [in RDM] … I am confronted with people who are normal but they get it more. And if you… It's like in a gym, you come there and there are all these people, they make you think like… You know? They look very strangely at you from, mwha, what is she going to do? You know? You immediately get a… What do you call it? A name. Let me put it that way.*
> *[…]*
>
> *Dido: They want to look good at the gym, you say. Do you think dance is also about looking good? That it has to look good or?*
>
> *Theresia: Ehm… no, you can be more yourself.*
>
> *Dido: Does that work?*
>
> *Theresia: Yes.*
>
> *Dido: And how does that feel?*
>
> *Theresia: Good, so you don't have to pretend to be different from who you are.*

Expressing the true self in dance facilitated strong connections between participants. Self-expression also freed (or further freed) participants from the "Parkinson's" or "MS" label that in turn allowed for the re-defining of oneself in line with inner feelings.

> *Christine: It was a way to let it out and to express yourself, really okay, I am not my MS, there's me, and it's like okay, to be in that beautiful surroundings and then to be in that environment and then to, with the music as well, just to learn the body in a different way and to become aware of different parts of your body, because before I almost ignored my legs, I was like [grrr] they've let me down [grr], it was kind of like my lower part of the body was almost like you know, I was like, I didn't accept it any more, it didn't work for me, and then to realize, okay, this all works together and there's still a lot of um, possibilities there.*

The encouraging artistic environment was critical to facilitating this transformation. With an emphasis on creativity and expression, participants could show themselves and discover "the dancer inside," rather than feeling that their movements had to look a certain way. This supported the embrace of the whole body-self and inspired confidence.

> *Jolanda: I am standing tall right now because I am proud of myself… again. It took a long time, yeah, yeah. But I think, I was really thinking, um, thanks to the dance, completely. Yeah.*
>
> *Anna: How do you think dance helped you to feel proud again?*
>
> *Jolanda: Ehm… well the fact that I am who I am and I show it in how I dance. That's also, that's a part of me, and I always danced, when I was little I was always dancing, so somewhere inside of me the dancer is still, yeah, the dancer came alive [laughs] yeah completely. And in, for my health also, and for my passion, I do a lot of things, but I think dance is my real passion. Yeah.*

Some participants even said they ultimately became thankful for their illnesses because it awakened a new passion and opened the door to dancing, particularly in stimulating environments previously seen as exclusive. Importantly, this was experienced as a silver lining, not a panacea.

Connecting Frank's (1995) notions on the body

Dance provided participants with an enjoyable, supportive, and accepting environment in which they

Figure 4. Escape, expand, embrace (3) by Renée Kool

could connect with others. This community embraced everyone who joined it, which supported participants to be themselves and let go of trying to be someone else; this meant accepting to a certain extent the body's contingency. By learning to trust themselves and others through dancing in this space, participants could regain some bodily control and express the self through the body. Being oneself in dance awakened the "dancer inside" and passion, which cultivated desire and optimism.

The infinitely transformative nature of rediscovery

Dancing transformed participants experiences of and beliefs about their bodies and selves, yet living with illness continuously presented participants with physical and emotional challenges that were also transformative. This led to changing abilities and a dynamic, continuous process of rediscovering the self and body. Some challenges were fleeting, while others, like surgeries and injuries, had to be dealt with over longer periods of time. There was a need to rediscover "how my body works *now"* each day in life and in dance. The infinite process of rediscovery was less daunting with the support of others. Participants experiencing such challenges described feeling frustrated that they had lost the freedom of movement they had found through dance. Adapting to new challenges was confronting, yet the desire to do so was strong. Sometimes, changes in the body meant stepping away from dancing physically and finding new paths to continually rise above, expand, and embrace the self, but this did not take away from what dance had given (Box 2).

Box 2. A brief description of Christine's dance journey.

"Diagnosed with MS in 2001 … my world started to shrink, doors closed, many activities ceased, and along came a loss of self-esteem and confidence.

It was tough to deal with, especially after having had a very lively career in the world of fashion, design and journalism, travelling extensively and with a busy social life. "Who I was" had come to a somewhat abrupt end and I was not sure how I would carry on.

I found it difficult to accept and deal with my MS condition, until I heard about a research group looking into the effect of dance on MS … Let me add, that since I was a little girl, I dreamt of being a ballet dancer, but never ever danced!

Right from that moment, when dance entered my life in 2015, my life changed considerably, and a whole new exciting chapter opened up.

Dancing with several artists, combined with several years of travelling, demonstrations, talks and sharing my dance experience …

And then … end of 2019 …

A series of brain-strokes resulted in a huge loss of mobility, strength, energy and capability. I had to once again cease activities, cancel plans—everything stopped, on pause.

Where it all goes from here I have no idea … all I can say is that at least now I am in a positive state, through the grace of dance."

Discussion

This participatory study explored the lived experience of dancing with Parkinson's or MS in an inclusive setting. Findings suggest that dancing in a nonjudgmental environment supported participants to transform and integrate their bodies and selves through escaping, expanding, and embracing. Importantly, the lived experience was a shared experience, in which rediscovery occurred through dancers and facilitators giving and receiving trust, energy, acceptance, and support. Participants' relationships with the dance community also became reciprocal, as they used their rediscovered selves to share and advocate for its transformative power with the goal of inspiring others living with illnesses to realize what is still possible for them.

Both the experiences of illness and dance were characterized by transformations. After the onset of illness, participants described meaningful activities, relationships, and other aspects of their identities falling away. Life was described as becoming smaller and the direction participants felt they were heading was down. The introduction to dance supported participants to realize that there were still possibilities for growth, giving them agency to transform life's direction to being up and out. The introduction to dance and the related experiences that followed could be described as "epiphanies": significant, interactional turning-point moments (Denzin, 1989). Dancing altered the "fundamental meaning structures" in participants' lives by changing beliefs about and experiences of their bodies, selves, and social situations. There was an immediate desire for more as participants sensed dance, and the freedom and passion it provided, was good for them. Participants described this as feeling like something inside them (the dancer) had "come alive." Other stories of dance and Parkinson's have emphasized the revitalization of sensualities and joy of life through music or memories, with dance being understood as a space where sensuality can be reclaimed for a person living with Parkinson's (Christensen-Strynø et al., 2021). This "sense of aliveness" in the context of dance has also been described as characterized by affect, or the "motion of emotion" (Barbour & Hitchmough, 2014). Affect has been argued to be more influential than effects in participatory arts as being "moved" emotionally can shift perspectives and ignite desire to engage with people, ideas, and activities (Thompson, 2009). Affect is intrinsically a part of the act of dancing, which suggests that not only are the aftereffects of dance important to understanding its impact, but also the experience of dancing that occurs in the moment.

The "rise above the self" that occurred while dancing provided an escape from illness and the negative stress that accompanies it. Dance has been previously demonstrated to provide an escape through altered states of consciousness, diversion from stress through fantasy, or refocused awareness from painful to pleasurable bodily feelings (Hanna, 1995). Participants in this study similarly described getting into a flow, imagining they are great star dancers, and discovering pleasure in their bodies through dance, shifting the focus from control to contingency by developing new relationships with the body (Frank, 1995). In RDM classes, illness is simultaneously accepted yet not the focus, giving participants freedom and permission to express themselves through movement in whatever ways they can. This was liberating, and being given freedom seemed to create space for the escape. Other research into dance and Parkinson's has similarly demonstrated that dancers may experience freedom of movement in part through freedom from stigma and disease (Houston, 2019). Dance has also been described by people living with Parkinson's as a catalyst for various aesthetic associations, including memories of a younger body or abstract conceptualizations of vitality and youth (Christensen-Strynø et al., 2021). Importantly, feeling accepted and being free to express the self through the body allowed the two to integrate and be embraced in this escape.

Previous research into dance and Parkinson's has found dance to increase participation in daily activities (Holmes & Hackney, 2017) and provide opportunities to "get involved" and "give back to the community" (Bognar et al., 2017). Our findings elucidate how such participation can give participants the opportunity to rediscover previously lost aspects of their identities and to discover new talents, interests, and passion. Parkinson's has been described as a transformative journey during which the self must be continually re-evaluated through discarding traits, activities, and abilities while discovering new ones (Rutten et al., 2021). The opportunity to maintain and develop social identities has been identified as an important influence on well-being and hope (Soundy et al., 2014). Similarly, changing identities through the loss of valued activities and roles has also been described as a challenge for people living with MS (Desborough et al., 2020), and the maintenance of pre-existing social identities and the capacity to join new social groups has been described as important for adaptation and the integration of the old and new self (Tabuteau-Harrison et al., 2016). Becoming a dancer and contributing to the expansion of the dance community led to the development of old and new aspects of identities for participants in this study, integrating the past and present body-self. It also provided a new, meaningful purpose in life. This purpose was characterized by a quest (Frank, 1995)—to keep moving, create, and share the experience of dance with others to show how powerful it can be.

In contrast to previous research into dance and Parkinson's or MS, which have emphasized the regaining of control (Beerenbrock et al., 2020; Holmes & Hackney, 2017; Scheidler et al., 2018), our findings suggest dance both supported participants to feel more in control of their bodies and come to terms with the body's contingency by embracing their body-selves the way they are. This likely had to do in part with the space created by RDM facilitators and the type of dance being practiced. The RDM environment was inclusive and welcoming, and being in an accepting environment has been previously described as important in the acceptance of one's body-self when living with disability (Taleporos & McCabe, 2002). Furthermore, RDM participants were engaged in improvisation, which transcends dance styles and promotes possibilities for all abilities, whereas the majority of existing studies were focused on particular dance techniques, which require mastery of steps or movements. Despite the potential of dance to help participants regain control of their balance and other mobility problems, the reality of such chronic, progressive illnesses is that stress, treatments, or other forces beyond a person's control can result in new physical and emotional challenges. When the body-self inevitably changes, dance that emphasizes creativity rather than mastery seems to provide opportunities for endless embodied discovery and growth. Improvisational dance may therefore be a powerful way of coping with challenges and embracing how the body works at any given moment by continually bringing its possibilities, however large or small, back into the foreground.

Limitations (and possibilities)

This study explored the lived experience of dancing with Parkinson's and MS in an inclusive dance group. Because RDM is truly inclusive, there were also people living without illnesses in the group, yet only one was interviewed and he also had a connection to MS as a carer; thus, the study was still "disease-oriented" in a sense due to our research question. Further research should explore RDM and other inclusive dance programmes holistically to understand the phenomenon from multiple perspectives.

This research invited participants to look back on their dance journeys, many of which spanned years. The findings highlight dance's potential to continuously support individuals adapting to living with illness over time. Due to the transformative and unpredictable nature of Parkinson's, the search for stability in life has been suggested to be a continuous process rather than a one-time intervention (Rutten et al., 2021); the same is likely also true for MS. Dance seems to be able to provide the "magical key" needed for such a process. Longer periods of data collection (i.e., years) are therefore warranted to fully capture dance's impact and the social identities that are maintained and develop from the experience.

Conclusions

The shared, lived experience of dancing with Parkinson's or MS in this group is characterized by movements of the body, emotions, and life. Through dancing in a nonjudgmental environment, people living with Parkinson's and MS can indeed become communicative bodies as defined by Frank (1995) on a quest to dance and share this experience with others. Dance supported participants to more easily embrace the body's contingency by showing its possibilities. Through expressing the self through the body, participants could integrate the two by becoming dancers. Dancing with others provided opportunities to connect with people living with illness, and those who are not, in an accepting environment; it also taught participants the value of giving and accepting support. Dance eventually became a passion, producing desire to dance for the self and for others. Naturally, there are many activities that may produce such passion, supporting people to become communicative bodies and embrace illness as a quest; however, dance may be a particularly healing way to share one's story because the body is the medium through which that story is being told.

> *Hannie: My illness and discovery of dance feel more and more like that search for something special. I've already discovered a lot of it, but it's like climbing Everest. The top is still in the clouds. When you get up there, you see overwhelmingly beautiful things. Sometimes there is a cloudy day and you don't get to see much. Occasionally, the disease will bounce you back down a bit and you have to gather yourself together to get back up. The quest never ends and sometimes forces you to look for other paths to get out above those clouds. I have a lot of respect for Christine, who was indeed thrown back by her strokes, but is climbing again in a different way. She continues to inspire. For me she remains the ultimate "dancer."*

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Hannie (J.E.M.) Meijerink is an expert-by-experience living with Parkinson's and a patient researcher with the Dutch Parkinson's Association (Parkinson Vereniging). She discovered her love for dance and dance music after being diagnosed with Parkinson's. In 2019, she joined Foundation ReDiscoverMe as a participant and in 2021 performed in their production of Ik en de Ander. Prior to being diagnosed with Parkinson's, she worked professionally as a veterinarian.

Christine Gravemaker-Scott is an expert-by-experience living with Multiple Sclerosis. She discovered the dance in 2015. She danced with Foundation ReDiscoverMe as a participant, and in 2018 she performed a duet choreographed by Damar Lamers from Foundation ReDiscoverMe at DanceAble#2 in the Holland Dance Festival. Prior to being diagnosed with Multiple Sclerosis, she worked professionally in fashion design and journalism.

Lucia Thielman obtained her Bachelor of Biomedical Sciences at the University of Leiden and her Master's degree in Management, Policy Analysis and Entrepreneurship in Health and Life Sciences. She worked as a researcher at the VU in Amsterdam, and she is currently an action researcher at the Leyden Academy on Vitality and Ageing.

Renée Kool (1961) is an artist and artistic researcher. She graduated in 1991 from the Gerrit Rietveld academy for fine art and design in Amsterdam. While developing her art practice she went on to study Art Theory and Emergent

Media. She never worked in a fixed medium nor with fixed materials, rather on assignments, often for temporary art projects in public spaces with multimedial outcomes. Lecturing in art and design education has always been an integral part of her practice.
As an artist and lecturer, she collaborated with specialists from many different fields like architects, urbanists, composers, translators, actors, and dancers. Since her Parkinson's diagnosis, she is experimenting with different, less intensive forms of art production and with co-authorship. To unlock the trailblazing intersectional character of her oeuvre, Kool has started building a database containing all possible documents about the development of her works and their exposition. She recently stopped regular teaching and started dancing again, for dance was her very first artistic endeavour.

Natalie Lewin is a dance instructor who works with people living with chronic conditions, including Parkinson's and Rheumatoid Arthritis. She worked with the Dutch organization Dance for Health as an instructor and also in a movement group using a physiotherapeutic approach.

Tineke A. Abma is the Executive-Director of Leyden Academy of Vitality and Aging and Professor "Participation of Older People" at Leiden University Medical Centre, dept. Public Health & Primary Care in The Netherlands. For over twenty-five years, Tineke Abma has been researching themes closely related to the participation of clients and citizens, participatory research, arts-based methods, ethics and diversity. Her work aims to improve the social inclusion and quality of life of people, especially those in marginalized positions. The last two years she has supervised the first Dutch national study into the value and impact of arts in long-term care for older people. Abma is the author/editor of a number of books, including *Evaluation for a Caring Society* (IAP Press, 2018) and *Participatory Research for Health and Social Well-Being* (Springer Nature, 2019).

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