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An exploration into the experience of family caregivers for people living with dementia in a community dance class

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ABSTRACT

Community dance has been used as an arts-based approach in healthcare, key for expression in populations who may not typically have access to dance. This study sought to conduct an empirical exploration of family caregivers' perceived psychosocial wellbeing when regularly participating in community dance classes. Community dance can be defined as an activity that can enable creative, expressive, and inclusive experiences for those that take part, and, for this study, both caregivers and people living with dementia were able to participate in community dance classes of this nature. Using a qualitative research design, three family caregivers for people living with dementia diagnoses participated in semi-structured interviews. Using Interpretative Phenomenological Analysis, the findings suggest that the spousal and adult-child caregivers perceive emotional and psychological benefits from dancing. The caregivers in this study emphasised that their community dance participation provided them with respite, reaffirmed relationship connectivity between caregiver and care-receiver, social engagement, and a rediscovered sense of identity. Findings offer insight into the appropriateness of dance as a method for alleviating potential psychological and social stressors experienced by family caregivers, advocating for greater availability of community dance classes for those experiencing dementia and their caregivers.

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Introduction

Dementia is an umbrella term referring to a range of progressive, neurodegenerative conditions including Alzheimer's disease, vascular dementia, dementia with Lewy bodies, and frontotemporal dementia, amongst others. Symptomology is unique to each dementia diagnosis and individual, often affecting cognitive functioning and having a significant effect on memory, language, emotional behaviour, judgment, perception, and attention (Herron, Rosenburg, and Skinner 2016). Worldwide, it was estimated 35.6 million people lived with dementia in 2010, with numbers expected to almost double

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every 20 years, to 65.7 million in 2030 and 115.4 million in 2050 (Prince et al. 2013). Although diagnoses of dementia are largely associated with older populations, early onset dementias, such as familial Alzheimer's disease and frontotemporal dementia, occur in people aged as young as 30 years. There is no current cure for dementia, with no medical treatment existing to prevent its occurrence. Existing medicine aims to slow down the worsening of some symptoms, with efforts focused on providing a better quality of life for the person and their caregiver (Downs 2000; Martyr et al. 2018). Through dementia progression, the condition can affect the wellbeing of the individual and caregiver. Caregiving has been described as a public health issue, meaning dementia care is likely to become more prominent with the increased ages of subsequent generations (Schulz and Martire 2004). This epidemiological transition illustrates that understanding caring for those living with dementia, and the lived experience of the people providing that care, is likely to become increasingly, and globally, relevant.

The focus of this study is located in the context of community dance. Community dance is a diverse field, broadly defined as an opportunity for anyone, anywhere, regardless of age, gender, sexuality, race, disability, or socioeconomic circumstance, to experience dance (Amans 2013). Often community dance takes place outside of statutory provision such as education or professional performance contexts, and according to the People Dancing Professional Code of Conduct in the United Kingdom (2021) creates, 'a "safe" space where individuals can fulfil their human and creative potential, where they feel positive about themselves and are respected and valued by others, enabling them to grow, develop and build positive and active relationships within their wider communities.' Participants have the right to be creative and express themselves through the medium of dancing in a community, having the potential for positive impact on psychological and social wellbeing.

Existing literature illustrates clear psychosocial dimensions commonly experienced by caregivers for people living with dementia. These include, but are not limited to, relationship distance between caregiver and care-receiver, an increased felt responsibility by the caregiver, reduced social engagement, and subsumed identity (Georges et al. 2008; O'Shaughnessy, Lee, and Lintern 2010). Informed by these dimensions, the aim of the present study was to advance current empirical understanding of caregiver experience in community dance classes by framing it within a gerontological and sociological study. This study utilised semi-structured interviews, analysed through Interpretative Phenomenological Analysis, to ask how both spousal and adult-child caregivers of people living with dementia psychosocially experience community dance classes.

Literature review

Relationship connectivity

The nature of the relationships between the family caregiver and care recipient can fluctuate throughout dementia progression. Spousal carers feel an increased sense of separateness from their partner, as they experience a loss of shared activities and shared understanding (O'Shaughnessy, Lee, and Lintern 2010). The feeling of being equal partners can morph into a power imbalance, where one may have an increased dependency on the other. This causes spousal caregivers to experience a sense of powerlessness,

lack of control, and increased emotional distance from the person living with dementia (O'Shaughnessy, Lee, and Lintern 2010). Perceived loss of relationship can also impact negatively on the physical and psychological wellbeing of adult-child caregivers (Fauth et al. 2012).

Despite this, shared activity participation may promote positive outcomes amongst those living with dementia and their caregivers (Roland and Chappell 2015). Moments of 'connectedness' are valued amongst spousal caregivers, with participants seeking continuity of their relationships through leisure activities facilitating social interaction and connection (O'Shaughnessy, Lee, and Lintern 2010, 253). Leisure activity has also enhanced the enriching, positive features of caregivers' relationship with the person they care for rather than the difficulties faced in dementia caregiving (Carbonneau, Caron, and Desrosiers 2011). Through experiencing activities together, caregivers for people living with dementia are said to feel satisfied and fulfilled in their caregiving role (Hellström, Nolan, and Lundh 2005). Here, it is possible that shared participation in community dance classes can facilitate increased connectedness between caregiver and care receiver.

Identity and responsibility

Through increased responsibility of a caregiving role, carers reported that their sense of self was subsumed by the role of caring (O'Shaughnessy, Lee, and Lintern 2010). Since the person living with dementia may have an increased dependency on the caregiver, this can lead to family caregivers subjectively feeling a cessation of solely feeling like a spouse, friend, daughter, or son and instead primarily identifying as a 'caregiver' (Eifert et al. 2015). Orona (1990) suggests that this changing or loss in identity is affected by the caregiver's own social structure, wholly dependent on the multiple social roles they hold, like being a mother, daughter, or partner, and how they identify themselves in each social situation. The aforementioned author also outlines how transformational the reciprocity between caregiver and care-receiver can be, in shaping caregiver identity. The potential loss of relationship with the person living with dementia may contribute to the loss of the caregiver's identity, by virtue of kinship being part of the human condition (Orona 1990).

The process of caring for another's daily needs can be emotionally stressful and physically exhausting. Georges et al. (2008) contest that caregivers for people living with severe to moderate dementia can neglect their own welfare and spend above ten hours caring per day. The shift of responsibility on caregivers can lead to them finding it difficult to manage their own needs (O'Shaughnessy, Lee, and Lintern 2010). When compared to spousal caregivers, adult child caregivers may experience more stress as they add caregiving to other responsibilities such as childcare and employment, whereas spouses can consider caregiving to be part of their existing marital duties (Conde-Sala et al. 2010). To maintain a healthy, social lifestyle, it is recommended that carers take regular breaks, see friends and family and maintain hobbies and interests throughout the progression of the condition (Benbow et al. 2008). Roland and Chappell (2015) found that 2.6% of carers stated that meaningful activity provided respite, acting as a break from the full-time nature of caring. Mediating a level of responsibility as a caregiver can be undefined and constantly re-evaluated.

Social engagement

When undertaking a larger amount of responsibility, caregivers may experience an involuntary loss of external social engagement. With this in mind, healthcare professionals may need to consider caregivers' social life when providing support to avoid social isolation. Dementia not only affects people living with dementia diagnoses socially but also the caregiver, as corroborated by a survey conducted by the Alzheimer's Society (2018). Almost 60% of carers experienced feelings of guilt when seeking external, formal support or socialising with other people and groups. Perceived guilt over caring complacency differs dependent on the relationship of the caregiver to the person living with dementia. Adult children caregivers reported higher levels of guilt in the Caregiver Guilt Questionnaire than spousal caregivers (Romero-Moreno et al. 2014). Feelings of guilt may lead caregivers to avoid engaging in social and leisure activities as it could pose a moral conflict about the importance of maintaining their own wellbeing whilst also providing care for the person living with dementia (Romero-Moreno et al. 2014).

Academic enquiry into the social effects of community dance on caregivers for people living with dementia who also partake in the dance activity is scarce with the notable exception of Kontos et al. (2020). The authors placed specific focus on the potential of dance in improving social inclusion for people living with dementia and family caregivers. Social inclusion is often multidimensional and can be impacted through appropriate access to resources and activities across socioeconomic, social, and cultural societal domains (Skinner et al. 2018). In turn, social inclusion through the medium of dance can encourage the participants, both people living with dementia and their caregivers, to connect to a wider collaborative community. The findings presented by Kontos et al. (2020) show that playful and imaginative dance engagement can challenge the stigma of existential and irreversible loss associated with dementia. Instead, community dance supports social inclusion for people living with dementia and family caregivers in a 'failure-free' environment (Kontos et al. 2020, 7). The authors identify a dancing environment that promotes social inclusion and averts stigma and hierarchy should be made more widely accessible to people experiencing dementia. In turn, this approach may contribute towards removing barriers to dance for wider communities.

Community dance

The arts can act as an alternative to the reliance on biomedical methods in alleviating dementia symptoms, which can, in turn, positively impact caregiver experiences. Dance activity has been recognized as a mode of expression, aiding the psychosocial wellbeing of marginalized and disadvantaged communities (Houston 2005). The relevance of research in dance for health has gained traction in recent years, notably with the Arts Enterprise with a Social Purpose (AESOP) research. Social interaction was described as fundamental in fostering wellbeing and social health outcomes in dance for older adults (AESOP and BOP Consulting 2018) Although not specific to communities with people living with dementia, the authors conclude that there are 'active ingredients' in dance that makes it suitable as an arts-based intervention in health and wellbeing contexts.

Social prescribing, sometimes known as community referral, is a means for medical professionals to prescribe activities to individuals for health and wellbeing purposes, due to its potential in fostering social interaction (The Kings Fund 2017). A social prescription constitutes referring individuals to non-clinical services, like dance, to provide holistic health and wellness care either instead of or in combination with medicinal prescriptions (Clements-Cortés and Yip 2019). The definition of health and wellness, in the remit of social prescribing, advocates for encompassing people's economic, environmental and psychosocial circumstances into how they are cared for. Thus, according to Chatterjee et al. (2017), arts on prescription aims to support individuals with mental and physical health issues through active participation in activities, in order to encourage self-expression, self-esteem, and social contact through access to dance and, more broadly, the arts.

Incorporating a process-centred approach into dementia care is pivotal to acknowledge the social impact of dance and, thus, the social psychology of caring for a person living with dementia. Currently, research on arts-centred health programmes for dementia focuses predominately on reducing the behavioural and psychological symptoms of dementia (Skinner et al. 2018). However, dance movement therapy arguably adopts a different research approach; there is a focus on reporting person-centred outcomes like quality of life and encouraging a sense of community rather than objectively measured clinical outcomes (Beard 2012, 642). Although this study crucially acknowledges community dance as distinct from dance movement therapy, this research illuminates dance as a process-orientated modality, capturing the potential expressive value of movement. Dance utilizes the body and can be described as a universal form of communication and human expression (Nakajima 2011). From an anthropological perspective, Hanna (1979) theorizes that dance is inherently communicative and a resource that humans can draw upon as social animals. Carers for those with dementia are reported to experience loss of social engagement (Vikström et al. 2008) and empowerment for those who are socially excluded can be accessed through participation in community dance (Houston 2005). By applying a qualitative methodology from a dance science perspective to traditionally sociological and gerontological academic fields, the particular idiosyncrasies within community dance practice are given precedence. In dance research, caregivers are commonly interviewed about their experiences of dance in reference to facilitating care interventions for people living with dementia (Hamill, Smith, and Röhricht 2012). It was therefore deemed necessary to give a sole voice to formerly undocumented narratives of caregivers of people living with dementia dance experiences. Blending theoretical perspectives from health and gerontology alongside existing literature in community dance and art can illustrate the possible psychosocial benefits derived from community dance participation.

Due to the scarcity of existing enquiry about caregivers of people living with dementia experiences of community dance participation, an exploratory study was deemed appropriate. This study explored the following research question; how do caregivers of people living with dementia perceive their psychosocial experiences in community dance classes? The secondary research question asked how do caregivers experience community dance classes with specific reference to social engagement in a community setting, the relationship dynamic with the person with dementia, and feelings of responsibility towards their care?

Methodology

A qualitative research design and methodology were selected for this study, focussing on three family caregivers to allow for in-depth engagement with each individual (Smith and Osborn 2008). The aim of this study was to gain a comprehensive understanding of each participant's subjective experience.

The age of the caregiver participants ranged from 42 to 57 years ($M = 50.3$ years, $SD = \pm 6.24$). All participants were female and identified that they had been acting as caregivers for a minimum of three years, with participants attending community dance classes weekly or biweekly over a period of between six months and four years at the time of interview. The participants were recruited from existing community dance classes facilitated by professional dance companies in the United Kingdom that promoted the ethos that everyone has the right to enjoy dance. The community dance classes were advertised specifically for people living with dementia and encouraged companions and caregivers to attend alongside. Class content included both standing and seated dance activity with some movement including the use of props like scarves and bouncy balls. Participants were able to both improvise their own expressive movement and learn dance company repertoire. The dance genres of the community dance classes themselves were not directly specified but were provided by ballet and contemporary dance companies and organisations. All participants stated they provided at least 20 hours of care per week, with two of the respondents providing round-the-clock care. Two participants were spousal caregivers and one provided care for a parent. The nationalities of participants included Indian, British, and Belgian. All participants were either unemployed or self-employed. The people the participants were caring for had dementia diagnoses including Alzheimer's disease and early onset behavioural variant frontotemporal dementia.

Participants took part in one semi-structured interview via Skype (Microsoft 2018) to accommodate the care activity the participants needed to provide. All interviews were audio-recorded (Sony PX470 Digital Voice Recorder PX Series) and lasted between 60 and 100 minutes, dependent upon the detail of participant response (see Appendix A for interview guide). Audio recordings were transcribed by the first researcher and member checked to ensure validity and credibility of data collected. After reviewing the interview transcripts, participants consented to the use of verbatim quotes with no amendments or withdrawals made to transcripts.

Interpretative Phenomenological Analysis (IPA) enabled detailed exploration of the participants' accounts through in-depth, qualitative analysis of case-by-case experiences (Smith and Osborn 2008). The aim of the analysis was to understand the content and complexity of meaning within the participants' context. Transcripts were openly coded following IPA guidelines provided by Smith and Osborn (2008). To stay open and honour individuality in each interview transcript, a form of analytical bracketing was employed. This process of open coding aimed to bracket emerging themes and ideas from the first transcript analysis, from the second and the third transcripts. This analytic process allowed new themes to emerge with each transcript. Although this form of analytic bracketing is acknowledged to be imperfect, this approach in IPA is adopted 'where possible' to consistently maintain rigour in the analytic process (Smith, Flowers, and Larkin 2009, 100).

To begin, the transcript was read several times whilst looking for initial themes. Subsequently, emergent theme titles were generated with notes being converted into concise phrases that accurately captured the quality of participant response. This process was repeated with each transcript, independently. The themes were then connected into hierarchal clusters and were not selected purely on prevalence but through the richness of particular participant passages and the context in which they were delivered (Smith and Osborn 2008). The themes and phrases were then identified and discussed with the second researcher and two further colleagues experienced in qualitative analysis. They performed a secondary analysis on anonymized interview transcripts to validate themes and ensure credibility and trustworthiness. The first researcher extracted verbatim quotes as primary source material to ensure confirmability of themes and support understanding of participants' experiences.

Ethical approval was granted by Trinity Laban Conservatoire of Music and Dance Ethics Committee. Written and verbal informed consent was obtained from participants preceding data collection and each participant was reassured that they could withdraw from the research at any time, without detriment. After completion of interviews, Skype accounts used by the first researcher were closed with online Skype contact details removed as they were no longer required. Audio files of recorded interviews were also deleted after the transcription and coding process to comply with local ethical approval requirements, as they were deemed to have no long-term value once transcription and data analysis had taken place. Participants were informed that the interview transcripts were to be stored for up to 10 years from completion of the study, in accordance with General Data Protection Regulations (GDPR) (Information Commissioner's Office 2018). Participants were given advisory contact numbers should they wish to seek further support. All anonymised data was stored electronically as password-protected and digitally encrypted files, again in accordance with GDPR requirements (Information Commissioner's Office 2018). Identification codes were assigned to each participant, to ensure anonymity and confidentiality of responses.

Findings and discussion

All participants conveyed their experiences as caregivers in community dance classes. The analysis identified six overarching, synthesized theme dimensions: a) perception of caregiver identity, b) mediating caregiver responsibility, c) community dance as caregiving respite, d) relationship connectivity, e) communal, social engagement, and f) availability and access of dance classes.

Perception of caregiver identity and mediating caregiver responsibility

Shared responsibility of caregiving was experienced by participants, enabled through a supportive and safe environment. Participants described trusting class facilitators and fellow participants in the class, meaning they were able to, 'switch off from being the totally, 100% carer, somebody else can take that responsibility . . .' (Participant 3). Such comments illustrate how caregiver responsibility is negotiated and exchanged fluidly between the participant and class facilitators.

When asked about the environment of the dance class, Participant 2 described it as a place where they could relinquish control, ‘... because of the dance and the music ... I can feel I can put that kind of protective, not just mask, but scaffolding aside and be more kind of, you know, free.’ The clarified, metaphorical use of ‘scaffolding’ as a descriptor suggests just how unwavering caregiving responsibilities can feel. All three caregivers reported still feeling a level of responsibility during the dance class, where they ensured the person living with dementia was comfortable, safe, and ‘following’ what was happening. Despite this, where experiences of dementia caregiving can be restrictive, dance was an empowering influence on the caregivers’ identity; ‘... so you keep on kind of being told that its small, that things are kind of less, and so you do dance like this, it kind of expands, says, “no you’re not just that [a carer] actually there is a lot more ... it empowers you” (Participant 2). Illustratively, dance can transcend the previously identified psychosocial dimensions of caregiver experiences; by temporarily resigning caregiver responsibility, participation in community dance classes not only allowed participants to rest but also caregivers’ own participation contributes to maintaining their own autonomous identity.

Community dance as caregiving respite

Participants unanimously reported that attending community dance classes acted as a distraction from their daily caregiving commitments as, ‘... you could be having a really bad day, and then in that moment you just forget ... you just get totally involved in what you’re doing, the movement at that moment ...’ (Participant 1). Participant 3 also admitted she was ‘... looking to escape’ from her daily caregiving responsibilities and did so in dance classes by ‘... pretending I’m in a ballet class.’ Additionally, dance participation can act as a source of undivided concentration and involvement for the caregiver, distinct from everyday existence, as dance is ‘... capable of creating such alternative realities’ (Palo-Bengtssona and Ekman 2001, 164). Further, dancing led to a feeling of release and loss of inhibitions, whereby all participants said they felt a loss of self-consciousness when dancing as, ‘... when you do a dance class like that, you lose your inhibitions ... it doesn’t feel embarrassing because everyone is doing the same thing’ (Participant 1). Similarly, another stated, ‘... I wouldn’t have dreamt of going to a dance class on my own ... so the fact that we go to dance classes where it doesn’t matter how well or not well you do it, it’s perfect’ (Participant 3). This sense of freeness might be interpreted as a feeling of freedom of expression, where the participant felt free to go beyond their perceived experiential limits.

Unique to dance activity, Participant 2 described a transcendence of self, where ‘... I was in a trance as if all my body was electrified ... so you kind of give yourself up and you feel you can just let go.’ Participants detailed that dancing allowed for complete absorption in the moment and loss of self-consciousness, all of which parallel dimensions of a flow state (Csikszentmihalyi 1990). Flow encourages a space for participants to temporarily cease criticising or analysing themselves (Hefferon and Ollis 2006), a salient comment from participants of the present study. Partaking in dance activity alleviated feelings of guilt and complacency that one participant experienced as a caregiver. The participant stated, ‘... that guilt that I used to feel before we did the dance class, “oh what do I do with her” you know ... I used to beat myself up about it quite a lot, so it’s taken some of that away’

(Participant 1). Indeed, Participant 1 expressed a sense of accomplishment and fulfilment when attending community dance classes as, ‘... I really feel like, on that one day, I’ve kind of, done something good for mum, encouraged her to do something good for herself. And so that feeling of guilt is not as bad.’ It might be interpreted from such participant accounts that for these people, dance activity promoted an autotelic experience in which they simply enjoyed the activity for the sake of activity alone (Csikszentmihalyi 1990); participants appeared to allow all of their attentional resources, otherwise focused on caregiving responsibilities, to be directed to total absorption in the moment of dancing.

Furthermore, participants’ opportunity to focus only on dancing for this period, led temporarily to less worrying about their caregiving responsibilities as, ‘... afterwards, I find that for me, whatever’s going on that I’ve been stressing or worried about, it doesn’t feel quite as bad *laughs*. It just is a little more manageable, you know?’ (Participant 1). The enduring effects of dance participation were transformative on life outlook, promoting a sense of wellbeing that can extend outside of the community dance class.

Relationship connectivity between caregiver and care-receiver

Connectivity in the relationship between caregiver and care-receiver was stimulated when partaking in dance community classes, where participants described feeling ‘very connected’ (Participant 2) and feeling like ‘... we’re actually together, and on the same page’ (Participant 1). According to Amans (2013), changes in dementia care culture have challenged stigma where caregivers are encouraged to focus on the existing capabilities of the person living with dementia. Dancing was regarded to be an activity where the person living with dementia is still present and, ‘... still able to contribute in a big way’ (Participant 2). Further, dancing acted as an activity they can still do together regardless of the dementia diagnosis. Connectivity could have been facilitated through playfulness, as participants reported this to be a positive dance experience as, ‘... it allows us to be ... not childish, you know what I mean a bit silly ... because I don’t mean to say childish as a demeaning thing because it’s a very positive thing, very playful and um, allowing and open’ (Participant 2).

Dance classes were also reported to be creatively inspiring and uplifting. Since dementia can change the personality and behavioural dispositions of those diagnosed (Herron, Rosenberg, and Skinner 2016) all participants stated they felt reconnected to the person living with dementia through dancing together. Participant 1 described ‘... it’s almost like having my mum back again as she was because she’s very animated ... so I get a glimpse of what, how she used to be’ and ‘... we were always people who danced, you know, as a couple, so I suppose that’s always what is good about it’ (Participant 3). Dancing not only allowed the participants to reconnect but also to reminisce, enabling a sense of coherence with past memories made together. Thus, dancing together may contribute to a caregiver’s perception of control over their internal lives with dance acting as a constant in, ‘... something that we can still sort of share’ (Participant 3).

Communal, social engagement

All participants reported dancing as an enjoyable activity emphasized through experience with other class attendees as, ‘... everybody has a laugh that’s the good thing, a bit of fun,’ (Participant 3) and ‘you’re doing it together ... and you can have a laugh, a joke ...’ (Participant 1). Participant 1 described these feelings as ‘... building a bond with each other’ and ‘... a kind of external family if you like, you know people you connect with.’ Another participant described the class as acting as a ‘hive thing with other people’ (Participant 2). Participants emphasized the importance of social relationships they had built through attending community dance classes.

The word ‘inclusive’ was used unanimously to describe the classes by all participants, illustrative of a sense of belonging with other caregivers attending. A sense of solidarity was also noted by all caregiver participants, where being in an environment with other caregivers leads to a sense of relatedness. Two participants described this feeling as, ‘everybody being in the same boat’ (Participant 1 and Participant 3). Dance classes acted as a place where caregivers felt they could share their experiences of possible caregiver isolation, ‘... it’s an opportunity to meet other carers as well, so you don’t, you’re not feeling on your own ...’ (Participant 1). Positive, personal experiences were derived communally, with all participants reporting the dance classes provided a safe space, where the environment fostered patience and understanding from fellow participants. Thus, joint participation in social dance activity, and the community it empowers, appears to help caregivers in this study to feel a reduced sense of isolation and increased validation in their caregiving experiences.

Availability and access to community dance classes

Availability and accessibility of dance classes were acknowledged amongst participants. In this study, Participant 3 described the exclusion she had previously experienced when participating in arts-based dementia activity, ‘... finding something we can both do together and both enjoy has been quite useful, rather than me taking him places where I sit there and he does it for like an hour ... That’s, you know, that’s effort ... and that’s exhausting.’ Arguably, the present study illustrates the possible benefits that access to dance activity can have on caregivers, as the same participant states, ‘I assumed I was just going to be sitting out ... and actually no! It’s for you as well! That was just, wow, you know, great.’

All participants in this study were either unemployed or self-employed, reporting they provide long hours of care. Free classes allowed for greater economic accessibility, and was stressed by Participant 2 and 3 as, ‘... you know, we’re having to pay for so much now because we just don’t get enough support, so the very fact that there was something offered free of charge was fantastic’ (Participant 3). There was a common awareness across all participants of the precarity of public funding such as those they attended. One participant stated, ‘... I don’t know how it’s funded I don’t know how long we can keep going but ... we’ll keep going until they say you can’t come any more’ (Participant 3). Caregivers in this study exhibited a mutual reliance on attending community dance classes weekly as fundamental to the structure of their lives. All displayed worries about what would happen if funding for the dance classes ceased as, ‘... it’s a kind of fear

I have, that they, they'll come to an end and what will we do, what do we fill that day with? To find something as special and as similar as these classes . . . I think that would be really difficult because these classes are quite special' (Participant 1). An awareness of the scarcity of community dance classes for people living with dementia was illustrated by all study participants.

There is a need to continue to emphasize the value of process-based programming in the community participatory arts. The evaluation of the intrinsic value of community arts activity, to those that take part and organisations contributing to dance for health and wellbeing, is a delicate issue epitomized by how the quality of dance provision can be measured by funding bodies. The feasibility of community art practice is often dependent on high levels of participation and attendance, sometimes alongside a pressure to create a performance outcome (Williams-Burnett and Skinner 2017). This type of information is widely accepted to show the quality of community art programmes, yet the very values in which community dance is grounded, encourage practice as a process of dance exploration rather than a performative product (Kuppers 2007). In this study, participants expressed their own hesitation, stating, ' . . . it's not about performing, it's about being able to let yourself go . . . enjoying the, relaxing in the movement' (Participant 3). Process-oriented approaches appear important to the participants in this study, in encouraging their participation without external pressure or expectation to do more than simply enjoy attending community dance classes with the person they care for in the moment. Such an approach can account for the social inclusion of caregivers of people living with dementia as a dynamic, ever-changing process that cannot be reliant on single measures of success alone (Skinner et al. 2018). Process and person-centered measurement of value in community dance class activity align with NHS England's social prescribing initiative, where they seek to find a more holistic approach to people's health and wellbeing (Clements-Cortés and Yip 2019).

Limitations

Due to the paucity of dance-specific literature on caregivers' experiences, this study was framed by sociological and gerontological literature. These studies often focus on leisure activity in general rather than dance participation in particular, perhaps limiting the scope of this study. Whilst thick descriptions of interview quotes have been included in this paper, complex content has inevitably been condensed to disseminate this research. Furthermore, using Skype to interview participants may have restricted building rapport. Observation of non-verbal behaviours may have been hindered partly due to camera positioning, whereas face-to-face interviews may have allowed for a greater understanding of the participants' gesturally expressive movement.

Recommendations for future research

Further dance-specific enquiry into the psychosocial effects of dance on those caring for people living with dementia is required. In previous literature, different modes of dance, including dance movement therapy and social dancing, have been categorized generally as 'dance work' to ' . . . capture the shared features of the various approaches of dance research in dementia' (Guzmán-García et al. 2013, 921). This crucially neglects the

dissimilarities of dance genres and related disparities between people's experiences. Existing research has recommended that the research community should broaden study parameters to further explore dance styles other than contemporary and ballroom for the wellbeing of older populations (Hwang and Braun 2015). In response to this, the genre of dance should be explored further in relation to the psychosocial experiences of those participating in community dance.

To explore caregivers of participants living with dementia holistic experiences in community dance, other qualitative research methods could be used in a multi-method research design to include observations, diaries, and interviews. Observations and diaries, in particular, can complement the use of interviews; observations can provide a valuable contextual understanding of the community dance class for both researcher and reader, and diaries can provide an intimate, personal account of the participant's psychosocial experience in community dance without any influence from the interviewer. Diaries can also be used as a form of self-reflection for the participant (Morrell-Scott 2018).

Future consideration should also be given to the psychosocial experience of all participants of community dance classes, including volunteers, facilitators, caregivers, and people living with dementia. Volunteers and facilitators could be asked about the intended purpose of the community dance class, and how the class is designed, and with whom in mind. This can illustrate holistically what the experience of a community dance class can have on all participants, rather than solely on whom the class is intended for.

Conclusion and implications

Community dance enabled the caregivers in this study to reconnect with the person they care for, facilitated a socially engaged, community environment with fellow caregivers, and empowered a temporary relinquishing of caregiving responsibility. The multitude of psychosocial benefits derived from community dancing illustrated the importance of access for this demographic, with specific regard to the availability of dance classes for people living with dementia and their caregivers. This study has the potential to contribute knowledge of the effectiveness of community dance classes as arts-based health interventions, adding valuable credence for dance on prescription from health professionals, both for the person diagnosed with dementia and their caregiver. The findings from this study suggest that community dance classes are well placed in the remit of arts prescription for social prescribing. Participants not only experienced self-expression, self-esteem, and a social community through community dance but also reported physical benefits, further solidifying the case for dance as exercise prescription (Chatterjee et al. 2017). Additionally, this study demonstrates how dance as a prescribed arts activity can alleviate the stressors specific to caregiving for people living with dementia by acting as a bonding activity, facilitating relationship reconnection, and providing a break from everyday care.

Therefore, dance as social prescription should be extended to include caregivers for people living with dementia. This is particularly relevant in current cultural and political landscapes in the United Kingdom, as by 2023 all GPs in England will be able to refer patients to community and arts activities. Part of the focus of the social prescribing initiative is to provide, '... specific support for carers, including respite care; short breaks; therapeutic activities; emotional and practical support ...' (Dayson and Bashir 2014, 5). These findings could therefore inform what areas of dance practice caregivers'

value for themselves and the person they provide care for, leading towards shaping how dance activity is led, facilitated, and structured.

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No potential conflict of interest was reported by the author(s).

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Appendix A. Interview Questions

Warm-up questions

- (1) Could you describe to me how you define a carer or caregiver? What you believe your role entails?
- (2) How long have you considered yourself a caregiver?
- (3) How long have you been attending the community dance class?
- (4) How far do you have to travel for this dance class?
 - (a) Would you consider this a long way to travel?
 - (b) What is the journey like? Bus? Underground?
- (5) What made you and your (husband/wife/relative/friend) come to the class, to begin with?
 - (a) Where did you hear about this dance class? Word of mouth or online for example?
- (6) What does your week consist of outside of this dance class?
 - (a) Do you go to any other arts classes for example?
- (7) So, tell me a little about your experience of dancing in this class
 - (a) What does the dance class consist of?
 - (b) What specific activities do you do?

Interview questions

- (1) What has physical activity meant to you throughout your life?
 - (a) Have you previously danced? Sports?
- (2) Tell me, how do you feel about coming to these dance classes?
 - (a) What is your day like before the classes?
 - (b) How do you typically feel before the classes?
 - (c) And could you explain to me how you feel at the end of the classes?
 - (d) Could you say more about this feeling?
- (3) What, if at all, about a community dance class appealed to you?
 - (a) Would you recommend dance classes to anyone you know who is a carer too as a result of your experience?
- (4) Could I ask you to reflect if you had any expectations of what a community dance class would be like before attending regularly?
 - (a) Does this expectation ring true now?
- (5) Could you speak about how you feel when you are dancing in this class?
 - (a) Could you give an example of what emotion you feel most regularly?
 - (b) Can I ask you to reflect on an anecdote where this feeling took place?
- (6) I'd like to know a bit more about your experiences, attitudes, and emotions as part of a group dynamic in class. So, what kind of attitude do you have towards being part of a dancing group specifically?
 - (a) How comfortable do you feel dancing in this class?
 - (b) Could I ask you to elaborate on those feelings?
- (7) Could you describe your relationship with your friend/spouse/parent during these dance classes?
- (8) Could you speak a bit about how you perceive your responsibility as a caregiver in this dance class?
 - (a) Could I ask you to say more about any help from social services/day centres/carers coming to house/community nurses you receive?
- (9) Can you tell me if this dance class may differ from your caregiving responsibilities?
 - (a) Can you elaborate further?
- (10) When thinking about the time outside of this dance class, I'm interested to know if you'd consider that attending the community dance classes has had an impact on your own quality of life or wellbeing?
 - (a) If any, what part of your quality of life has this dance class had the biggest impact on?
- (11) I would be very interested if you have any other feelings or thoughts, you'd like to share with me, to help me understand your experience of the dance class?