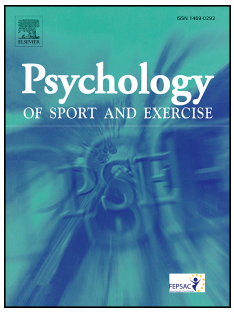

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Living in the mo(ve)ment: An ethnographic exploration of hospice patients' experiences of participating in Tai Chi

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Abstract

Purpose: Tai Chi is increasingly being used as a complimentary therapy in hospice care to help patients self-manage multiple and complex health needs. However, currently there is limited understanding of Tai Chi from patients' perspective, including what participation in this mindfulness based movement (MBM) exercise means to their experiences of living with an advanced, incurable disease. The purpose of this study was to explore outpatients' lived experiences of hospice-based Tai Chi in relation to mindfulness. **Methods:** 19 participants (15 females; 4 males, aged between 50-91 years old) with a range of advanced, incurable diseases (cancer, COPD, pulmonary fibrosis, pulmonary arterial hypertension) who attended day therapy at a local hospice took part in Tai Chi sessions. Using a focused ethnographic approach, multi-methods including 17 semi-structured interviews (averaging 40 minutes), participant observations (equating to 200 hours spent in the day therapy unit), and informal conversations were used to collect data over a 6 month period. Data was analysed using a thematic framework approach. **Results.** Four main themes were constructed that demonstrated participants' lived experiences of mindfulness during participation in hospice-based Tai Chi sessions. Main themes included: (1) mind-body respite; (2) being present with others; (3) tranquil and therapeutic atmosphere and; (4) physical limitations. **Conclusion**: Tai Chi may be an important therapeutic strategy for helping patients with advanced, incurable disease experience mindfulness. The findings of this study support the use of MBM exercises such as Tai Chi as a non-pharmacological adjunct to conventional treatments within palliative care settings.

Keywords: Tai Chi, palliative care, advanced disease, mindfulness, qualitative research, ethnography.

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Patients with advanced, incurable disease often live with multiple symptoms and side effects that negatively impact on physical (e.g., pain, fatigue, breathlessness), psychological (e.g., anxiety, depression, fear), social (e.g., isolation), and existential (e.g., loss of meaning) domains of well-being (Teunissen et al., 2007). The aim of palliative care is to help patients manage the adverse consequences of their disease and improve quality of life by adopting a holistic, patient-centred, and multi-disciplinary approach to healthcare (Twycross, 2003). As part of this approach, non-pharmacological and complimentary therapies such as physical activity are increasingly being used as a valuable adjunct to conventional medicine because they are non-invasive, cost-effective, and can help patients self-manage multiple and complex needs that change over time as their disease progresses (Javier & Montagnini, 2011).

Whilst physical activity is now generally accepted as a form of therapy for individuals with advanced, incurable disease (Albrecht & Taylor, 2012), during the 1980s, it was met with scepticism, with many doctors advocating rest as a more appropriate alternative (Jones & Alfano, 2013). Today, with increasing evidence to show that physical activity is beneficial and feasible in this population – and with many patients recognising the value of, and demonstrating enthusiasm about, participation (Oechsle et al., 2011; Oldervoll et al., 2005) - it is seen as an important adjunctive to standard therapy. One form of physical activity that is commonly used in healthcare settings is mindfulness-based movement (MBM) therapy (e.g., Yoga, Pilates, and Tai Chi). MBM seeks to integrate the mind, body, and spirit through movement-based exercises that involve a contemplative (i.e., inward and non-judgemental) focus on the embodied, kinaesthetic, and proprioceptive qualities of movement (La Forge, 2005).

Tai Chi represents one type of MBM that combines slow body movements with breath work and mental focus (Wayne & Fuerst, 2013). It is becoming increasingly popular with professionals in routine hospice care because of its accessibility; it can be adapted to a wide range of functional abilities and delivered safely to groups of patients with diverse needs (Hui, Cheng, Cheng, & Lo, 2008). Moreover, Tai Chi has been shown to provide physical and psychosocial benefits to those with a range of advanced diseases. Preliminary evidence, including data from randomised control trials and systematic reviews, has demonstrated the positive impact of Tai Chi on fatigue, balance, mobility, lung function, gait, mood and reduced anxiety among patients with advanced cancer (Hui et al., 2008; Zhang, Wang, Chen, & Yuan, 2016), chronic obstructive pulmonary disorder (COPD) (Guo et al., 2016), Parkinson's disease (Song et al., 2017) and heart disease (Ng et al., 2012). Moreover, data from mixed methods studies (Hägglund, Boman, & Brännström, 2018; Yeh, Chan, Wayne, & Conboy, 2016) has demonstrated improvements in social well-being (e.g., community involvement, increased social support) among patients with chronic heart failure.

Whilst current evidence on the benefits of Tai Chi participation is promising, empirical investigation on this topic has been dominated almost exclusively by quantitative research designs that use standardised outcome measures to assess changes in health and well-being variables. Consequently, little is known about Tai Chi from patients' perspective, including what participation means to their experiences of living with an advanced, incurable disease, and how these experiences are shaped by the environment of hospice day therapy. This is an important omission considering that hospices present one of the few places in the community where patients with advanced disease can access MBM therapies like Tai Chi.

In addressing this, qualitative methodologies are useful because they allow researchers to better understand the complex and nuanced processes through which people make sense of lived experiences in rich depth and detail (Sparkes & Smith, 2013). In

particular, approaches such as ethnography – in which researchers immerse themselves in the setting under investigation and collect multiple forms of data over prolonged periods of time – are well suited for exploring palliative patients' experiences of participating in Tai Chi within the context of hospice day therapy. One notable component of Tai Chi that may be important for improving patients' experience of living with advanced disease is mindfulness (La Forge, 2005; Wayne & Fuerst, 2013).

Mindfulness is the ability to deliberately pay close attention, without judgment, to one's immediate experience (Brown & Ryan, 2003). It involves moment-to-moment awareness of, and attention to, the quality of events and experiences that occur in the present (Brown, Ryan, & Creswell, 2007). Whilst mindfulness is increasingly being taught in palliative care to improve quality of life, there is a lack of evidence to support or refute its use for patients with advanced and chronic diseases (Latoracca et al., 2017). It has been suggested that mindfulness might be important for optimising well-being in patients who experience unrelenting physical discomfort and/or fear of the dying process by 'encouraging closer, moment-to-moment sensory contact with life, that is, without a dense filtering of experience through discriminatory thought' (Brown et al., 2007, p. 219). In contrast, it has also been suggested that its inward direction of attention toward physical discomfort can heighten body awareness and increase physical distress (Brown et al., 2007). Against this backdrop, more research is needed to better understand hospice patients' lived experiences of mindfulness.

The main aim of this study was to explore outpatients' lived experiences of participating in hospice-based Tai Chi. In responding to the data as the project evolved, the purpose of the study became refined to focus more closely on participants' lived experiences of mindfulness during participation in Tai Chi.

Methods

Research Design

A focused ethnographic research design (Knoblauch, 2005; Wall, 2014) grounded in a constructionist paradigm (Burr, 2015) was used to explore the aims of this study. Focused ethnography differs from ethnography in its traditional sense. Rather than spending large amounts of time (often years) permanently immersed in settings that researchers are unfamiliar with, instead, researchers engage in relatively short-term field visits (i.e., occasional rather than permanent immersion) in familiar settings within which they intensely collect and analyse data (Wall, 2014). This type of ethnography aligned well with this study because the primary author's [name removed for peer review] volunteering role within the day therapy unit (described in further detail below) enabled him to familiarise himself with the field and interact with participants prior to data collection. Though less time was spent in the field compared to traditional ethnography, this study still retained 'ethnographic intent' (Wolcott, 1999) in that it remained committed to an in-depth focus on a specific socio-cultural phenomenon as it occurred in everyday life (Knoblauch, 2005; Wall, 2014).

Participants

Participants were recruited using purposive maximum variation sampling (Etikan, Musa, & Alkassim, 2016). 19 outpatients (i.e., day case) (Female: 15; Male: 4) aged between 50-91 years old (M=74.2) took part in this study (see table 1). Inclusion criteria included patients who were: (a) diagnosed with advanced, incurable disease; (b) receiving care at [name removed for peer review] hospice; (c) participating in Tai Chi sessions offered at [name removed for peer review] hospice; (d) 18 years or older; (e) able to understand and communicate in English; and (f) capacity to give consent. Exclusion criteria included patients deemed too ill to participate in the study as determined by the hospice clinical team.

Procedure

Ethical approval was gained from the [name removed for peer review] (REC reference: 16/SC/0133) and the Research Governance Group at [name removed for peer review] (RGG reference: 2015-08). After approval was granted, the first author [initials removed for peer review] and physiotherapists who worked within the hospice's day therapy unit, initially approached patients face-to-face to enquire of their interest in participating in this study. Interested patients were provided with a participant information sheet before providing consent. Recruitment was an ongoing process and ceased once data saturation (Saunders et al., 2018) was achieved. Data saturation was a gradual and iterative process in which [initials removed for peer review] spent 6 months in the field continuously collecting and assessing data until what was being heard and seen started to repeat itself, thus no new understandings were being generated from data collection (O'reilly & Parker, 2013; Smith & Sparkes, 2016). This is not to say that 'objective truths' had been achieved, rather, it was a point where the research team was confident that they could richly represent participants' experiences of hospice-based Tai Chi whereby any additional data collection would have resulted in diminishing returns.

This study took place within the day therapy unit of [initials removed for peer review] hospice in [location removed for peer review]. Adapted Tai Chi sessions were offered weekly to patients and lasted for half an hour. Prior to entering the field for data collection, the first author [initials removed for peer review] volunteered within the day therapy unit twice weekly for a period of 2 months (April 2016-May 2016), which helped to legitimise his presence in the field and foster trusting and respectful relationships with participants. The first author [initials removed for peer review] maintained his role as a volunteer in the day therapy unit throughout the 6-month period of data collection. During his role as a volunteer [initials removed for peer review] spent time with patients in the communal room at the day

therapy unit, engaging in activities (e.g., quizzes, arts and crafts, gardening) and assisting with serving light refreshments and lunch. A considerable aspect of this volunteering role was spent sitting and conversing with patients about everyday subjects and common interests.

Fieldwork and Data Collection

Guided by a pluralistic approach to data collection (Chamberlain, Cain, Sheridan, & Dupuis, 2011), data was gathered using semi-structured interviews, participant observations, and informal conversations. These multiple sources of data provided different and complimentary perspectives on the phenomenon under investigation, resulting in a layered and contextualised account of participants' experiences of Tai Chi (Chamberlain et al., 2011). All data was collected by the first author [initials] during his immersion in the field.

One semi-structured interview was conducted with 11 participants. 6 out of the 11 participants were interviewed a second time approximately 4-5 weeks later. The initial interview guide was developed by [initials removed for peer review] who used his first 2 months in the field as a 'survey period' (Fetterman, 2010) to inductively generate relevant and appropriate questions that pertained to participants' physical, psychological and social experiences of Tai Chi participation within the context of hospice day therapy. For the 6 participants who took part in a second interview, clarification questions were mostly used to allow them to expand on the accounts that they had provided in their initial interview. All interviews were conducted at a convenient time for participants and lasted on average 40 minutes. They were digitally recorded and transcribed verbatim. Participant observations entailed actively engaging in 33 Tai Chi sessions to observe verbal (e.g., spoken interactions between participants) and non-verbal (e.g., facial expressions and body postures/movements) behaviours related to the purpose of the study. Observations were used to layer what was said during interviews with what was seen in the field (Kawulich, 2005). Informal conversations

with participants were used to tap into the everyday (and often overlooked) features of participants' experiences of Tai Chi that were sometimes missed within the formal setting of a semi-structured interview (Sparkes & Smith, 2013). Conversations took place whilst engaging in everyday hospice activities (e.g., arts and crafts, board games, casual conversations). Participant observations and informal conversations were recorded in the form of field notes. Fieldwork took place twice weekly over a period of 6 months (July 2016-January 2017). A total of 200 hours was spent at the day therapy unit collecting data.

Data Analysis

Data was analysed using a thematic framework approach (Ritchie, Lewis, Nicholls, & Ormston, 2013). This approach was chosen for numerous reasons. It offered a structured method that made it easier to deal with the voluminous data-set that was collected, was compatible with the underlying epistemology of the study, and allowed the context of participants' experiences to be preserved during the analytic process through an explicit and continuous movement between analysis and raw data (Smith & Firth, 2011).

Data analysis comprised of the following interconnected steps. First, interviews were transcribed verbatim and read multiple times to become familiar with the data. Second, transcripts and field notes were openly coded by labelling segments of text that related to participants' experiences of participating in Tai Chi. Third, an initial analytic framework was constructed by grouping similar codes and categories into themes and sub-themes. Themes and subthemes were then entered into a matrix and charted by moving raw data from transcripts and field notes into corresponding themes in the analytic framework. Fourth, a process of indexing occurred whereby the analytic framework was applied back to field notes and transcripts by highlighting parts of the text that aligned with the relevant theme within the framework. Finally, a collaborative process of interpretation took place, in which authors

[initials removed for peer review] acted as critical friends (Smith & Sparkes, 2016), drawing on theory and concepts to offer alternative explanations for findings. Thus, data analysis was 'abductive', involving a process of moving between induction (e.g., explanations and ideas stemming from the data) and deduction (e.g., using priori theory and concepts to understand patterns in the data) (Blaikie, 2018).

Throughout data collection and analysis, [initials removed for peer review] kept a reflexive journal as a way capture introspective (i.e., the personal impact of the research process) and intersubjective (i.e., the inter-relational factors that affected the research process) reflections (Finlay, 2002). In doing so, his experiential and intersubjective experiences in the field were used as a 'springboard for interpretations and more general insight' of the ways through which knowledge and interpretations of data were co-constructed (Finlay, 2002, p. 215).

Rigor

This study adopted a relativist approach to judging quality (Sparkes & Smith, 2009). A list of criteria based on the work of other scholars (Smith & Caddick, 2012; Sparkes & Smith, 2013; Tracy, 2010) was used as a starting point to guide the quality of this study. The list included: (1) rich rigor, which involved intense periods of time spent in the field (2 weekly hospice visits over 6 months) collecting multiple sources of data, resulting in deep and layered accounts; (2) sincerity, which was achieved by using a reflexive journal throughout fieldwork and consulting with 'critical friends' [initials removed for peer review] throughout data collection and analysis; (3) credibility, which occurred through triangulating data from interviews, observations, and informal conversations as a means to construct contextualised and thick descriptions of each theme; (4) resonance, which was achieved by providing thick, contextualised descriptions of each theme so that data may be transferable to

195 other (similar) settings; and (5) exploiting exceptional data (Phoenix & Orr, 2017), whereby
196 the researchers attended to, and incorporated, outliers (i.e., contradictory data) during the
197 construction of themes.

Pseudonym	**Age**	**Gender**	**Primary Diagnosis**	**Co-Morbidities**
Gloria	89	F	Pulmonary Fibrosis	n/a
Georgia	82	F	Cancer (unknown primary location w/ lung and liver metastases)	Arthritis, COPD
Doreen	86	F	Lymphoma	Type 2 diabetes, Dementia
Mary	71	F	Breast cancer	COPD
Lisa	74	F	Pulmonary fibrosis	Low mood
Elizabeth	91	F	Lung cancer (w/ choroidal metastases)	n/a
Jane	88	F	Gastrointestinal cancer	Low mood, anxiety
Shannon	71	F	Pulmonary arterial hypertension	Intestinal lung disease
Rachel	50	F	COPD	Low mood, anxiety
Leanne	85	F	Esophageal cancer	Bronchitis
Christie	68	F	Breast cancer (w/ lung and liver metastases)	Anxiety, depression

Karen	43	F	Carcinoma of stomach	Low mood
Debbie	63	F	Breast cancer (w/ bone metastases)	Paralysis from level T2
Judy	65	F	Lung cancer (w/ brain metastases)	Low mood, depression
Janine	73	F	Esophageal cancer	n/a
Roy	73	M	Lung cancer	n/a
Lee	84	M	Prostate cancer	n/a
Michael	87	M	Prostate and bladder cancer	n/a
Stan	68	M	Prostate cancer	n/a

Table 1: Participant Characteristics

Results

The following results section demonstrates participants' lived experiences of mindfulness during participation in Tai Chi. Study results include 4 themes and 2 sub-themes: (1) mind-body respite (including two sub-themes: (i) being present in the moment, and (ii) embodied peace); (2) being present with others; (3) tranquil and therapeutic atmosphere; and (4) physical limitations. Verbatim quotes are included in the main text below to provide supporting evidence.

Mind-body respite.

'Mind-body respite' characterised the ways in which Tai Chi helped participants to experience relief from the physical and psychological distress associated with living with

advanced, incurable disease by helping them to live in the present moment and experience their minds and bodies in pleasurable and peaceful ways.

Being present in the moment

Participants commonly reported how living with advanced diseased caused them to experience intense feelings of anxiety and worry. This was because their minds were often preoccupied by distressing illness-related worries over pain progression, the impact of their illness on friends and family, and fear of dying. One participant described how this left her feeling mentally 'all over the place' [Rachel, interview 1]. Tai Chi was an opportunity for participants to re-direct attention and awareness away from disease-related thoughts, and onto present moment-to-moment sensory and mental experiences. For example, focusing attention on breath-work, bodily sensations, guided visualisations, and the background music during Tai Chi helped participants to gain temporary respite from illness-related worries:

> I don't think [during Tai Chi] which sounds silly. I don't think because I'm concentrating on what I'm supposed to be doing. The music is a sedative sort of music, which stops you – no, it doesn't stop you thinking – you don't need to think. And listening to the voices which is calming helps you to not think about your condition and where you are. You just know you're safe and you don't have to think about anything else… not having to think makes such a big difference to my life. [Christie, interview 1]

Rather than ruminating over the past or dwelling on worries concerning the future, Tai Chi helped participants anchor their awareness in the present moment, leading to feelings of mental relaxation. Mental relaxation was characterised by states of tranquillity and contentment, fostering meditative states which helped to lodge participants' minds onto the present moment, thus helping to alleviate anxieties and feel mentally at ease:

> When I'm sitting sometimes my breathing starts getting bad because I'm anxious and it's about doing something to stop that anxiousness… and that is what it [Tai Chi] does for me, it relaxes it me…it just relaxes your mind. I suffer from anxiety, so for something to make me relax it's got to be good, and that what it does for me … when I'm relaxed like that, I'm not panicking, I'm not anxious … because once I start thinking, I start stressing. [Rachel, interview 2]

> You're just focused all the time and it's like you're removed from where you are even though you know you're there. You're just in the motion of Tai Chi because it never stops. So I think it is a mindful exercise, because you are focused on the motion of the whole thing… it is meditative to me. I feel totally relaxed at the end of It [Debbie, interview 2]

Embodied Peace

Many participants encountered illness and treatment-related physical symptoms, including pain, fatigue, muscle tightness, nausea, and body tremors. These symptoms led to experiences of embodied suffering and discomfort. Our analysis showed how engaging in Tai Chi provided participants with a sense of embodied peace by helping them to experience the present moment in physically pleasurable ways. For example, engaging in the slow and gentle movements accompanied by soft music fostered a sense of respite from feelings of bodily tensions and restlessness:

> I enjoy the music, and the part where you have to pretend to put water over your face. The last part is quite relaxing, which is really nice for me. I haven't been sleeping very well. I get about 1 or 2 hours sleep every night – I'm all tense and restless – I try to put the Tai Chi music CD on, along with other relaxation CD's but sometimes I am

> just too tense to sleep. So doing it here helps to give me some respite. [Stan, interview 1]

> Well I think just the movements because you've got like that pull of physicality, where you pull and that's quite relaxing to be tensing muscles and using them and then to relax them. You feel within your muscles the relaxation of contraction, and when you relax it feels greater relaxed because you've had the opposite of being contracted and then you relax it down, the relaxation comes out more as a physical thing … just in this relaxed state of being in a cocoon… it's like I'm wrapped in a relaxed state if that makes sense. … that half an hour makes you feel different for the rest of the day because all your tensions have gone. Even though you might be doing a quiz and you might not know the answers, you're still physically relaxed. [Debbie, interview 2]

Experiences of embodied peace were transformative in that they seemed to enable participants to feel physically *different*. Taking part in Tai Chi provided participants with a temporary escape from the physical discomfort of their disease by allowing them to enjoy the sensuality, pleasure and peacefulness that they were experiencing in the present moment. This sense of embodied peace involved feelings of physical relaxation that helped to 'calm the whole body from the top to the bottom' [Christie, interview 1]. For some participants, feelings of physical relaxation resulted in a peaceful 'high' that extended beyond Tai Chi sessions:

> I love it [Tai Chi] ... it's so relaxing... when I've been here [day therapy unit], I feel different again when I go home, it's lovely. I can really go with Tai Chi. It's peaceful… It's worth doing. That first time I did it, ooh, I was so tired but not in a nasty way, it was a lovely feeling. I would imagine it's the feeling like you get if

you're on heroin [laughs] which I don't know, never been on it, not yet anyway … it gives you a bit of a high but not in a nasty way, in a peaceful way… I don't know what it does to your body that makes you so peaceful. [Janine, interview 2]

By helping participants to feel physically relaxed, Tai Chi enabled them to experience the present moment in physically better and brighter ways through fostering sensations of physical renewal and restoration. Participants used words like 'cleansing', 'pleasant tiredness', 're-energised', 'reinvigorated', and 'rejuvenated' to describe these experiences:

When you're sitting on the chair, or laying down, it's almost as though something's washing through you and you rest… Almost like washing, cleansing … It's like being renewed. Like when you get out of bed in the morning, you feel groggy and then when you've washed your face, especially if you wash your face in cold water, it's re-invigorating… you feel better afterwards, I say refreshed. [Stan, interview 1]

Being present with others.

Practicing Tai Chi within a group comprised of fellow patients with advanced, incurable disease facilitated meaningful moment-to-moment peer interactions. It brought participants together under a shared activity and cultivated a sense of closeness through verbal (e.g., laughing, joking, and talking) and non-verbal (e.g., smiling and physical touch) interactions that facilitated the formation of, and reinforced already existing, relationships:

I think it's nice that they gather us…because when we come here [Tai Chi sessions], we're all doing different things. Everybody's doing different things. I think it [Tai Chi] brings us back together as a group … I think that a circle of friends is a good way to describe us, because we only meet once a week for a few hours so we know people more than others but we are all part of a group and I think the Tai Chi sort of

303 reiterates that because we come together as a group to do it …I think we are
304 connected. [Debbie, interview 2]

305 The social interactions shared during Tai Chi were integral to creating a calm and
306 relaxing environment which enriched Tai Chi practice. The collective participation in Tai Chi
307 helped participants to develop a soothing 'energy' that facilitated mindful movement:

308 I think a group working together builds up an energy and it builds up the healing
309 energy that then benefits everyone in the room, because Tai Chi is a healing process
310 and as you build the energy, the healing goes around and everybody gets a share of it
311 … I just feel that warmth of healing. [Judy, interview 1]

312 Some participants found that observing others during the sessions helped them to
313 (re)connect to bodily sensations of physical calm and peacefulness. For example, Rachel
314 spoke about how seeing other people in a relaxed state helped her to also feel calm and
315 grounded:

316 [you] can see other people and they're all doing the same thing and it's calming to
317 see that other people look calm as well, you know. [Rachel, interview 2]

318 Other participants commented on how being present with others during Tai Chi was
319 important in helping them to experience mindful states and thus reap the associated benefits.
320 For example, Judy emphasised the uniqueness of participating in Tai Chi with others at the
321 hospice because it helped her to experience a mode of introspection and meditation in ways
322 that were not possible when alone:

323 What I find very, very difficult to do at home on my own is meditate. To take myself
324 out and zone everything else out and just go into that sort of quiet calm state I find
325 very, very difficult if I'm on my own. If I'm in a group and were all doing it then I
326 can do it. [Judy, interview 1]

Whilst being present with others was experienced as beneficial for most participants, there were instances when it was seen as disruptive. For some participants, the group aspect associated with Tai Chi was viewed as a safe environment that allowed them to experience a quiet, inward connection with the self as opposed to a social occasion in which they interacted with others. At times, therefore, social interactions such as laughing and joking during sessions were experienced negatively because they interrupted participants' connection with the present moment:

> It annoys me when people laugh… I suppose I do think of it in the purest term, they should be more mindful and do it in a more mindful way, but that's just me being purist. But then I think there's times that I don't like it, it is disruptive in a way, I find then I have to focus back, but then I do say to myself, 'that's fine because that's what they do' and you know, you just accept it, they're part of the group and you have the generosity of partly accepting, don't you? ... [I] just think that sometimes it's a nervousness of people, because they're not sure if they want to sometimes go into that mindful place, or they don't know how to, or some people don't want to, or some people are embarrassed by doing the movements. [Debbie, interview 2]

Tranquil and therapeutic atmosphere.

The environment in which Tai Chi took place was integral for cultivating a tranquil and therapeutic atmosphere that was conducive to experiences of mindfulness. It was important that when participants were taking part in Tai Chi that the day therapy unit was calm, quiet, and free from distractions (e.g., slamming doors and people walking through the middle of sessions). This was so that participants were able to maintain their focus and attention on the gentle movements, music, and visualisations that were necessary for grounding their minds and bodies in the present:

> It's got to have the right atmosphere. I mean one week, the lady that I like did it, the other lady that did it last week, she were getting giddy and it weren't the same. It has to be in a special atmosphere … the atmosphere [has] to go with the voice and the movements … you couldn't just sit on the bus [and do Tai Chi] … that other lady turned the lights low, that helped, it certainly did, yeah. [Jane, interview 2]

There were various sensory cues (real and imagined) that were integral in creating the type of calming and tranquil ambiance that allowed participants to reap the aforementioned benefits that were associated with mindful movement. For example, many participants referred to the importance of the *sound* of soft music taking a central role in the room's soundscape, the *touch* of cold water as they imagined being under a waterfall, and *lights* being dimmed. These aspects of the environment were important because they acted on participants in and through their senses and determined the extent to which many participants felt capable of experiencing physical and mental states of peacefulness. For example, Jane recounted:

> The type of music is just so pleasant … it's so calm and so beautiful that it sort of goes inside of you, do you know what I mean? Your feelings when you're listening to it, not even doing the Tai Chi, just listening to the music I find is very restful … people moving around you isn't good, it needs to be in a calm, still atmosphere because then you get the benefit of lack of sound around you and just the music. [interview 1]

Those who led Tai Chi sessions also played a crucial role in contributing to the formation of a tranquil and therapeutic atmosphere. This was because they guided participants through the physicality of movements and mental imagery associated with Tai Chi. This allowed participants to ground themselves in the present moment through enabling

them to focus inwardly on the kinaesthetic qualities of movements and connect with visualisations of nature, as opposed to trying to remember the routine of Tai Chi:

> I think the [physio's] voice is important to listen to know what movement you're doing next really… I couldn't possibly remember it without the physio being there. I might remember a few. I might sit at home and think 'punching', 'sea.' I think the physio's guide us through the full half hour of the physicality of it, you know, they can't talk to us about being mindful but for the physicality I think it's important that they're there telling us… I like that because if I tried to do it at home I wouldn't remember so I'd have to ask [physio's name] to write it down and then you'd have to keep looking at the piece of paper because you won't remember, so it wouldn't be the same experience at all. [Debbie, interview 2]

Some participants also commented on how those leading Tai Chi sessions were able to contribute to the creation of a therapeutic environment in which they could reach physically and mentally mindful states through delivering instructions in a soothing and calm voice:

> She's [the physiotherapist] got a very calming voice. It can't be anybody with a shrewd voice doing it because that's a waste of time - a calming voice. Even then, the lady and I said to each other, 'we could've fallen asleep there', and it was genuine, we could've both fallen asleep. And that's not boredom – that's restfulness, you know what I mean? That's why. [Jane, interview 2]

Physical limitations.

Participants struggled to perform some of the Tai Chi movements due to physical limitations (e.g., reduced mobility) that were associated with their disease and co-morbidities. Moreover, certain movements exacerbated physical symptoms (e.g., pain, fatigue,

399 breathlessness, and oedema), disrupting participants' ability to fully participate in each
400 session:

401 It's [Tai Chi] very good but there are things you can't do. I can't do the leg
402 movements with this leg at all, because it hurts too much, and it will stay hurt for ages
403 ... You have pains in most places. I mean even the shoulder roll causes me pain and
404 I've got osteoporosis of the back, so you know, movements aren't always good. I
405 know they're gentle movements and everything, some I can do quite easily, no
406 problem. But anything where my body is being used to move, or to do anything, it
407 usually affects some part of me, you see. [Jane, interview 1]

408 Some participants (especially those who suffered from COPD and lung cancer)
409 required constant oxygen to aid their breathing. The continuous bodily movements during Tai
410 Chi sometimes caused them to feel breathless, resulting in bodily anxieties that caused panic
411 and distress:

412 I am used to doing things at 50mph all the time, but I can't do that so much anymore.
413 But that doesn't stop me from trying. Like with the Tai Chi today, I started out with
414 all of my best intentions to do it as well as I could, but my body isn't the same as what
415 it was before. I struggle with my breathing and at times when I get breathless, I can
416 panic. And I think that's what happened with Tai Chi today. I tried too much at the
417 start and just got out of puff. [Shannon, informal conversation]

418 As well as exacerbating disease-related symptoms, the inward focus on the body that
419 was cultivated during Tai Chi sessions was sometimes experienced negatively. This is
420 because it focused participants' attention on, and reminded them of, their deteriorating
421 bodies:

> I did have a negative moment in Tai Chi this morning. When we were doing the light and following your hand, it was the state of my hands. It made me focus on my hands and I didn't like it because they looked all pale and I do have a bit of arthritis in them. But it just seemed to accentuate how pale they were and I don't have full grip and they do shake when I don't mean to and I had this really negative sort of millisecond of 'I don't like doing this, its accentuating how horrible my hands look'. [Debbie, interview 1]

The exacerbation and reminder of physical limitations sometimes undermined participants' ability to experience the aforementioned benefits that were associated with Tai Chi. This was because they interrupted the pleasant bodily rhythms that were integral in grounding their minds and bodies in the present moment and, at times, resulted in participants experiencing their minds and bodies in unpleasant ways.

Despite the difficulties associated with participating in Tai Chi, physical limitations did not entirely preclude participants from taking part. This was because Tai Chi is a multifaceted activity involving more than gentle movements (e.g., guided imagery and music). Thus, despite physical limitations disrupting some aspects of their participation (e.g., gentle movements), participants were still able to take part in, and reap benefits from, other aspects of sessions (e.g., visualisations and listening to music). For example, Debbie, a participant paralysed from the waist down, shared:

> Obviously, it's difficult because I can't do legs, but I don't feel left out because I can't do legs because I just try and visualise my legs doing it. I don't sit there going 'I can't do this', I keep the mindfulness going by imagination and vision. [interview 2]

Discussion

To date, few studies have examined palliative patients' lived experiences of mindfulness during participation in hospice-based Tai Chi using qualitative methods. Through adopting a focused ethnography in which [initials removed for peer review] spent intense periods of time immersed in the cultural context of a hospice day therapy unit collecting multiple forms of qualitative data, we were able to produce a rich and contextualised account of participants' lived experiences of hospice-based Tai Chi. Accordingly, this study has the potential to lead to a comprehensive understanding of the benefits and challenges of participating in Tai Chi for patients with advanced disease and illustrates the importance of experiencing mindfulness during participation. The discussion below will consider the findings of this paper and how they relate to the literature surrounding Tai Chi, and physical activity more generally, in the context of advanced, incurable disease.

The theme 'mind-body respite' demonstrated how Tai Chi was a transformative experience in which participants were able to gain temporary relief from the physical and psychological distress that their illness caused them. These findings are consistent with those of previous studies that demonstrate the efficacy of Tai Chi in improving physical and psychological outcomes in this population (Hägglund et al., 2018; Hui et al., 2008; Song et al., 2017; Zhang et al., 2016). Moreover, the two sub-themes within mind-body respite extends these findings by adding novel insight into *how* and *why* Tai Chi led to such improvements.

'Being present in the moment' demonstrates how the various facets of Tai Chi (e.g., gentle movements, visualisations, and soothing music) helped participants to anchor their attention and awareness onto the present moment, as opposed to focusing on things that

worried them. In these ways, Tai Chi seemed to be an activity in which participants were able to experience 'immersive pleasures' through a concurrent process of detachment and attachment (Phoenix & Orr, 2014). That is, they were able to consciously focus on (thus attach their minds to) peaceful and pleasurable sensations that were occurring in the present whilst simultaneously detaching themselves from thinking about, and being consumed by, illness-related thoughts. Because this process facilitated experiences of mental relaxation and tranquillity, Tai Chi could be seen as an 'affectively transformative' experience (Throsby, 2013, p.15) that enabled participants to learn how to connect with their minds in pleasurable ways and experience an improved sense of well-being. This finding is particularly noteworthy, especially given that distressing psychological symptoms (e.g., worries and fears of the future/death, pain) can be persistent and unrelenting for patients (Teunissen et al., 2007) and that patients who experience these types of distress are up to four times more likely to have a desire for hastened death (Breitbart et al., 2000).

'Embodied peace' represented the ways in which Tai Chi helped participants to enjoy the present moment through providing them with temporary relief from the physical distress that their illness caused them. The progressive and uncontrollable nature of their illness, alongside disease and treatment-related symptoms and side-effects, were often at the forefront of participants' 'bodily intentionality' (aspects of lived experiences that the body is conscious of) (Allen-Collinson, 2009). In these ways, some participants seemed to experience 'chaotic bod[ies]' (Sparkes & Smith, 2005, p.84), which affected them in unrelenting and uncompromising ways. The gentle movements, calming music, and visualisations of Tai Chi were able to provide participants with relief from these forms of physical distress by re-directing their bodily intentions away from physical distress and onto sensory pleasures (Phoenix & Orr, 2014) such as physical relaxation, restfulness, and renewal. As such, Tai Chi participation was 'sensorially transformative' (Throsby, 2013, p.13) in that it enabled

participants to learn how to feel differently within their bodies through experiencing the present moment in physically peaceful and relaxing – as opposed to chaotic – ways. This is an important finding considering that physical symptoms such as pain, fatigue, and general weakness are commonly reported to be the most debilitating symptoms for patients with advanced disease (Teunissen et al., 2007).

'Being present with others' demonstrated the importance of group practice in facilitating mindfulness during Tai Chi. These findings support the work of others underscoring the importance of group participation in Tai Chi (e.g., Hägglund et al., 2018; Yeh et al., 2016) and physical activity more generally (e.g., Malcolm et al., 2016; Paltiel, Solvoll, Loge, Kaasa, & Oldervoll, 2009) in patients with advanced, incurable diseases. They also extend these findings by demonstrating the mechanisms through which the group contributed to mindful practices during Tai Chi participation. Accordingly, they provide support for, and may be explained by, Cormack, Jones, and Maltby's (2018) grounded theory of group processes during mindfulness-based interventions. Participants' experiences of mindfulness during Tai Chi seemed to resonate with the concept of a 'community in meditation'. Mindfulness was experienced as an interdependent and relational process in which participants seemed able to generate and share their experiences of mindfulness between one another through meaningful social interactions that fostered a 'collective energy, warmth, calmness and tranquility' (Cormack et al., 2018, p.10). These interactions were seen as important for facilitating feelings of connectedness within the group and helped participants to create a culture in which mindfulness was valued (Langdon, Jones, Hutton, & Holtumm, 2011). Furthermore, it was important that the physiotherapists who led Tai Chi sessions maintained a non-judgmental attitude and guided participants (verbally and non-verbally) through the gentle movements and visualisations. Together, these group processes were able to enrich the communal experiences of Tai Chi and help participants to enter

deeper states of mindfulness than would have been possible compared to if they had engaged in Tai Chi at home or on their own (Cormack et al., 2018).

'Tranquil and therapeutic atmosphere' demonstrated the importance of the environment in which Tai Chi was conducted. In order to reap the benefits that were experienced through the mindful aspects of Tai Chi, participants' noted that it was paramount that the room in which it was conducted was calm, free from distractions, and quiet so that they could fully focus on, and immerse themselves in, the soothing music and imagery during sessions. This is a novel contribution to the literature because it provides a situated account that highlights the ways participants' experiences of Tai Chi are located in, and affected by, the setting (i.e., hospice day therapy) in which it is conducted. The importance of the surrounding hospice environment during Tai Chi sessions may be understood through the concept of 'therapeutic landscapes' (Gesler, 1992). These are described as ''places, settings, situation, locales, and milieus that encompass the physical, psychological and social environments associated with treatment or healing' (Williams, 1999, p. 2). The hospice environment in which Tai Chi was conducted seemed to consist of a variety of real and imagined therapeutic structures (e.g., calm music, dimmed lights, and visualisations of nature) that were able to foster states of mindfulness, thus contribute positively to participants' experiences of Tai Chi by helping them to immerse their minds and bodies in the present moment.

'Physical limitations' highlighted how some participants struggled to engage in certain Tai Chi movements due to disease- and treatment-related physical limitations, and how the introspective focus that it fostered sometimes made participants feel uncomfortable because it highlighted the deterioration of their bodies. The manner in which participants' physical limitations precluded participation in Tai Chi, and undermined their ability to experience the benefits of mindfulness, may be understood through the concept of

'interrupted and apprehended motion' (Phoenix & Bell, 2019, p.50). That is, physical symptoms felt/exacerbated during Tai Chi appeared to unexpectedly and unwantedly remind participants of the contingencies of their deteriorating bodies and interrupt the pleasant bodily rhythms that were associated with mind-body respite (Phoenix & Bell, 2019). This finding is at odds with much of the literature surrounding the impact of Tai Chi (and physical activity more generally) on patients with advanced, incurable diseases whereby much of the research has conformed to the 'exercise is medicine' narrative. Such studies have (often uncritically) advocated exclusively for the positive outcomes and accessibility of Tai Chi as an intervention for patients with a variety of advanced, progressive diseases (e.g., Hui et al., 2008; Li et al., 2014). Through highlighting the potentially negative ways in which patients with advanced disease may experience Tai Chi, this finding presents an original contribution to the field, while also supporting recent critiques of the 'exercise is medicine narrative' (Williams, Hunt, Papathomas, & Smith, 2018). Future research guided by qualitative inquiry is needed in this area to broaden our understanding of the nuances and complexities that accompany Tai Chi (and physical activity) engagement in patients with advanced, incurable disease, including the potentially negative and messy ways in which they may experience participation.

Collectively, these findings support the use of hospice-based Tai Chi as a non-pharmacological adjunct to conventional treatments for patients with advanced, incurable disease. They also support a recent Hospice UK report which underscored the importance of ensuring that palliative patients have adequate access and provision to rehabilitative palliative care therapies/services (e.g., Tai Chi) within the catchment area of where they live (Hospice UK, 2015). In achieving this, hospices may act as 'diffusers' in their local communities (e.g., places that provide adequate provision and access for patients to be physically active) of Tai Chi and MBM interventions more generally (McLeroy et al., 1988).

To contextualise these findings, it is appropriate to highlight some limitations of the study. First, many aspects of participants' experiences of Tai Chi were deeply sensuous and embodied. A potential limitation of this study was that it relied on traditional forms of analysis and representation that have been critiqued with regards to their ability to fully communicate the complexity and richness of sensual and embodied experiences (Sparkes, 2016). Future research that draws on different types of creative analytic practices (e.g., creative non-fictions) would greatly enrich our understanding on this topic by digging deeper into, and more evocatively representing, these aspects of participants' experiences. Another potential limitation of this study was that the observations and experiences analysed are those of a predominantly female group (f=15, m=4). While future research should strive to address this through actively seeking out the experiences of men, we maintain that this limitation can be mitigated through opportunities to generalise our findings using naturalistic generalisability (Smith, 2018). In other words, males involved in hospice-based Tai Chi are likely to identify (albeit partially) themselves and their experiences within our findings. That we did not identify significant within-sample differences between our female and male participants further supports this. Remaining on the theme of gender, another limitation of our study relates to the observational data that was collected (e.g., fieldnotes), including decisions regarding where to 'hang out', and what conversations to initiate and when, being overseen exclusively by a male researcher [initials removed for peer review]. We must acknowledge, therefore, that these (inter)actions were equally gendered. This is by no means to imply the findings are less trustworthy (indeed, difference here may have helped with rapport, access, elaboration etc.) but worth noting given the gender breakdown of the group being studied. The involvement of [initials removed for peer review], who offered guidance on research conduct, data analysis and representation of findings may have further mitigated this.

Conclusion

The aim of this study was to explore hospice outpatients' lived experiences of hospice-based Tai Chi in relation to mindfulness. Through adopting a focused ethnographic approach, this study provides a situated account of how participation in Tai Chi facilitated experiences of mindfulness. The various aspects of Tai Chi (e.g., gentle movements, breath-work, visualisations, soothing music, and surrounding environment) acted as a gateway into the present moment in which many participants were able to experience temporary relief from the distressing aspects of their illness. In this regard, Tai Chi mostly helped participants to experience their minds, bodies, and social surroundings in pleasurable and peaceful ways. Integral to the benefits that were experienced through the mindful aspects of Tai Chi was ensuring that it was conducted in a calming and therapeutic setting. This study supports the use of Tai Chi as a non-pharmacological adjunct to conventional treatments in helping to manage and address the multifaceted healthcare needs of patients with a range of advanced, incurable diseases.

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742

Highlights

- Participation in Tai Chi helped hospice patients to experience mindfulness by grounding their minds and bodies in pleasurable moment-to-moment experiences.

- Experiences of mindfulness were important for helping patients with advanced, incurable disease experience temporary relief from illness-related distress.

- Tai Chi is a valuable adjunct to conventional treatment within palliative care because it can help patients experience improved psychosocial health and well-being, however, some participants may struggle to engage in certain Tai Chi movements due to disease- and treatment-related physical limitations.

Declaration of interests

☒ The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

☐The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: