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Tai Chi as therapy for alleviating experiences of social death in people with advanced, incurable disease: An ethnographic study.

Abstract

Advanced, incurable disease is a highly stressful and traumatic life event that can lead to losses of social identity, social connectedness, and losses associated with bodily disintegration. The combination of these losses makes it difficult to remain socially active and sometimes results in experiences of social death. However, few studies have explored the role of group-based hospice activities for mitigating the impact of social death in people with advanced, incurable disease. The aim of this study was to explore the personal and social experiences of participating in hospice-based Tai Chi among people with advanced, incurable disease, including its impact in mitigating experiences of social death. A focused ethnography was used to guide this study. Six months were spent in a local hospice day therapy unit in England collecting data through multiple methods, including 17 semi-structured interviews, 200 hours of participant observation, and informal conversations with 19 participants (15 females; 4 males, aged between 50 and 91). Data were analysed using a thematic framework approach and represented using traditional tales and ethnographic creative non-fictions (CNF). Two main themes were identified: (1) fostering social connections and meaningful support; and (2) the protection of a collective identity. An ethnographic CNF ‘moving and being together’ presents these themes in evocative, engaging, and accessible ways. Study findings demonstrate the value of group-based Tai Chi for mitigating experiences of social death in people with advanced, incurable disease. Ethnographic CNFs are a valuable way to represent lived experiences of illness in palliative and hospice care populations.

Keywords – Tai Chi, Palliative care, Social death; Ethnography; Creative Non-Fictions

Introduction

Social death and advanced, incurable disease

Advanced, incurable disease represents the stage of the disease trajectory where a person's illness does not respond to curative treatment (Twycross 2003). The progressive and irreversible nature of disease often results in a multitude of uncontrollable losses (of physical functioning, independence, social identity/roles, and the future), that eventually results in physical death (McKechnie, MacLeod, and Keeling 2007; Parkes 1998). Biological/physical death reflects a discrete and universal event in which 'the body is considered to have died and ceased functioning for life' (Borgstrom 2017, p.5). Coming to terms with physical death often causes individuals and their families profound suffering (Boston, Bruce, and Schreiber 2011; Wilson et al. 2007). However, some people's experiences of advanced illness can also result in a different type of death; social death.

The term 'social death' first appeared in the 1960's and has been researched in various contexts including: hospitals (Glaser and Strauss 1966; Sudnow 1967), dementia care (Spicker 2000; Sweeting and Gilhooly 1997) and hospices (Lawton 2000). Whilst it has been defined in numerous ways (see: Kastenbaum 1977; Sudnow 1967), social death occurs in extreme and profound circumstances, and refers to the experience of being perceived/treated as if already dead or non-existent (Borgstrom 2017). It may be divided into self- and other-perceived; self-perceived social death is when a person views themselves to be as good as dead to others around them, whereas other-perceived social death occurs when people treat/view someone as non-existent or invisible (Kalish 1968). These types of social death represent how advanced illness can degrade a person's perceived sense of belonging to a group, culture, or place (Králová 2015). Because social death refers to an extreme event in which a person is stripped of self- and other-perceived social value and may experience a loss of personhood, it is different to simply feeling isolated or lonely (Králová 2015). Rather, the process of becoming socially non-existent prior to physical death typically involves an *amalgamation of interconnected losses* that can result in a person feeling disconnected from social life. The main characteristics of social death include accumulated losses of social identity, social connectedness, and losses associated with bodily disintegration (Králová 2015).

Loss of identity refers to the ways in which illness affects how a person understands themselves in relation to others and how this impacts their sense of self (Králová 2015). A review of qualitative research has demonstrated the importance that people with advanced disease place on maintaining social and professional roles, but how disease progression often disrupts their ability to engage in the everyday activities that allow this, resulting in feelings of being dependent on, and a burden to, others (McCaffrey et al. 2016). *Loss of social connectedness* is characterised by a degradation of interpersonal relationships and a breakdown of social and community life in which a person becomes 'deprived of meaningful human interaction' (Králová 2015, p.240). This is common in people with advanced, incurable disease who often report feeling socially isolated (Ek and Ternestedt 2008; McKechnie, MacLeod, and Keeling 2007). Finally, *loss associated with bodily disintegration* is related to the impact of physical deterioration on an individual's perception of their social identity and ability to connect with others (Králová 2015). Physical decline can make it difficult for some individuals to engage in social activities outside their home. This inability often leads to the dissolution of relationships, shrinking of social worlds, and feelings of exclusion from everyday life (Ek and Ternestedt 2008; Lawton 2000).

The accumulation of these losses can significantly undermine an individual's perception of their social well-being (Králová 2015). Against this backdrop, it is important that palliative care services effectively respond to people's multifaceted social needs so that they can help to prevent and alleviate experiences of social death and improve quality of life.

Palliative day care and group-based Tai Chi

Palliative care is a type of healthcare for people living with advanced, incurable disease. It focuses on improving quality of life and alleviating suffering through adopting a holistic, person-centered, and multidisciplinary approach (Twycross 2003). Group-based activities are used within palliative care to help people improve their quality of life and may be one way to help relieve experiences of social death. One type of group-based activity that is becoming progressively popular in a palliative day care is Tai Chi (La Forge 2005). Tai Chi is an adaptable form of Chinese martial art that combines slow movements with breathing and cognitive skills (imagery and mindfulness) in order to facilitate the flow of Qi ('vital energy' said to be central to health and well-being) throughout the body (Klein 2017; Wayne and Fuerst 2013). A central facet of Tai Chi practice is the cultivation of a strong sense of community through tuning individuals in with other people and objects that are located within their social and natural environments (Wayne and Fuerst 2013).

Evidence from randomised control trials and systematic reviews demonstrates the positive impact of Tai Chi on fatigue, mobility, lung function, gait, balance, mood, and anxiety in people with advanced disease (Ćwiękała-Lewis, Gallek, and Taylor-Piliae 2017; Song et al. 2017; Zeng et al. 2014). Whilst a small body of mixed-methods research illustrates that Tai Chi is an important form of social support and community involvement in people with chronic heart failure (Hägglund, Boman, and Brännström 2018; Yeh et al. 2016), most research in this area has used quantitative designs to examine physical and psychological outcomes. Consequently, understandings of the personal and social experiences/benefits from participation for people with advanced disease remains unexplored.

Qualitative research designs such as ethnography offer a promising approach to explore how interventions such as Tai Chi might shape experiences of social death in people with advanced, incurable disease (Sparkes and Smith 2013). Because of its explicit focus on culture, ethnographies are well-suited to projects seeking to understand the social and relational aspects of Tai Chi participation within specific contexts (Atkinson 2016). The aim of this study was to use a focused ethnography to explore the personal and social experiences of hospice-based Tai Chi in people with advanced, incurable disease, including its impact in mitigating experiences of social death.

Methodology

Focused ethnographic inquiry

A focused ethnographic approach (Wall 2014), grounded in ontological relativism and epistemological constructionism (Sparkes and Smith 2013), was used to guide this study. For a study to be considered an ethnography, it must contain 'ethnographic intent' (Wolcott 2008) by exploring how shared patterns of behaviours, beliefs, values, and emotions are embedded in, and shaped by, specific sociocultural settings. Focused ethnographies differ from traditional ethnography in various ways. Rather than studying unknown cultures, researchers are familiar with the group/setting that they are researching and explore distinct research questions (Knoblauch 2005; Wall 2014). Furthermore, instead of researchers permanently immersing themselves in the field over long periods, focused ethnographies are typified by shorter periods of, and occasional, immersion in the field featuring intense data collection and analysis (Knoblauch 2005). Focused ethnography was adopted in this study because it offered a pragmatic and efficient way to capture multiple forms of contextually-bound data on specific topics within healthcare settings in ways that can contribute to the improvement of care/care processes from the 'emic perspective' (Fetterman 2010; Higginbottom, Pillay, and

Boadu 2013). This aligns with palliative care's person-centered approach to care and research.

Setting

This study was conducted at a hospice Day Therapy Unit (DTU) that provides outpatient care for people with life-limiting illnesses. Day therapy provides one day a week where service users attend the hospice and access its services whilst spending time with others who have advanced disease (Corr and Corr 1992). During this time, the multidisciplinary healthcare team deliver a care plan that addresses people's multifaceted needs. The care plan involves a wide range of pharmacological and non-pharmacological therapies. This includes the opportunity to participate in Tai Chi sessions. These half-hour sessions were offered to service users once a week and led by physio/occupational therapists. Their purpose was to provide an opportunity for attendees to engage in group-based mindful movement with others.

Methods

Gaining entry, volunteering, and legitimisation

Entering the DTU involved [name removed for peer review] liaising with key gatekeepers (the hospice director and activities coordinator) to negotiate access. This was achieved by volunteering within the DTU for a two-month period (April 2016-May 2016) prior to data collection, a role that was continued throughout and after data collection and spanned a 3-year period (April 2016-Dec 2019). The volunteering role entailed [name removed for peer review] spending two full days each week within the DTU working alongside the hospice team and other volunteers. As part of this role, he engaged in variety of activities, including conversing with people, making/serving refreshments, and taking part in social activities. This allowed [name removed for peer review] to assimilate into the cultural surroundings of the hospice, legitimise his presence, and form trusting relationships with those who attended, many of whom participated in the current study.

Participants

Participants were recruited using a maximum variation sampling technique (Etikan, Musa, and Alkassim 2016) which we applied to understand our research question from as many angles as possible by actively recruiting a cross-section of participants who represented the range of diagnoses that are commonly present within day therapy. In total, 19 participants (F=15; M=4) aged between 50-91 years old (mean=74.2) were recruited. All participants had a diagnosis of advanced, incurable disease (see [reference removed for peer review] for more information on demographic information and inclusion criteria).

Fieldwork and data collection

Fieldwork refers to researchers fully immersing themselves within the culture that they are studying and collecting multiple forms of data (Fetterman 2010). In this study, [name removed for peer review] spent six months in the field adopting a pluralistic approach to data collection, which involved the *integration* of multiple methods (participant observations, semi-structured interviews, and informal conversations) (Chamberlain et al. 2011). 17 semi-structured interviews (of which six were second interviews), lasting on average 40 minutes, were conducted. Second interviews were conducted with ‘key informants’ who were particularly articulate in initial interviews, thus were seen as people who could potentially provide further detailed and rich insight/reflections on their personal and social experiences of Tai Chi (Fetterman, 2010). Participant observations took place over 33 Tai Chi sessions in which [initials removed for peer review] actively engaged in sessions whilst observing verbal and non-verbal reactions of participants. Informal conversations took place whilst engaging in everyday activities as a volunteer in the DTU. Participant observations and informal conversations were recorded as field notes. Each data collection method was used to provide a differing, yet complementary, perspective on the topic under investigation in a way that one method alone could not achieve (Chamberlain et al. 2011). In total, they equated to spending 200 hours in the field. More details on data collection methods can be found in [reference, removed for peer review].

Data Analysis and Representation

Data were analysed using a thematic framework approach (Ritchie et al. 2013) and comprised of the following iterative steps. Interviews were transcribed verbatim and read multiple times. Interview and field note data were then openly coded, labelling segments that related to the research's aims. An initial analytical framework was developed by grouping similar codes into categories and categories into themes. The analytic framework was indexed by applying it back to transcripts and field notes, highlighting parts of the text that aligned with the corresponding theme. At the interpretation stage, authors [removed from peer review] acted as 'critical friends' (Smith and Sparkes 2016), drawing on relevant sociological and psychological theories/concepts (e.g., social death) to understand, explain, and challenge each other's understandings of findings. As such, data analysis was 'abductive', fluctuating between induction and deduction (Blaikie 2018).

The analytic process was also embedded within the write-up and representation of findings (Sparkes 2002; Richardson 2000). Thus, writing was treated as a method of inquiry, using multiple forms of representation to think about and represent participants' personal and social experiences of Tai Chi in different ways (Richardson 2000). In doing so, we drew on two complementary forms of representation - traditional tales and ethnographic creative non-fictions (CNFs) – to both *tell and show* readers about participants' experiences.

Traditional tales have three characteristics: (i) experiential author(ity) (the researcher removing oneself from the write-up); (ii) the participant's point of view (empowering the voice of participants) and (iii) interpretive omnipotence (explaining data through connecting it to theory) (Sparkes 2002). This form of representation can provide readers with compelling insights into participants' social worlds by *telling* readers about their experiences of Tai Chi and how these related to social death (Sparkes & Smith, 2013). Despite their strengths, using traditional tales alone are limited because they offer only one way of knowing that often omits important features from our understanding of our research questions (Douglas and Carless 2009). That is, the complexity, nuance, and contextually bound aspects of participants' experiences of hospice-based Tai Chi and social death could not be done justice through telling the reader about them alone.

Therefore, we also decided to use ethnographic CNFs. These are:

> a type of creative analytic practice that tells a story which is grounded in research data and draws on literary conventions …. Each story is fictional in form yet factual in content. It is grounded in real events and people's lived experiences that a researcher observed in some fashion (e.g. interviews, participant observation, internet blogs) whilst 'being there' in the field. (Smith, McGannon, and Williams 2015, p.59)

The two forms of representation are aimed to be mutually enriching in demonstrating the different and complex ways that social death and the impact of Tai Chi was experienced by participants. Accordingly, ethnographic CNFs aimed to complement traditional tales and engage readers by drawing on literary techniques to *show* – instead of simply tell – them about participants' experiences through inviting them into their lives in evocative and insightful ways.

The use of creative analytic practices have been advocated by ethnographic scholars in producing compassionate, empathetic, and participant-centred pieces that push the boundaries through which we may understand our data (Atkinson 2016; Wolcott 2008). Whilst CNFs have been used in other areas of the sport and exercise literature – for example, coach-athlete-coach triads (O'Malley, Winter, and Holder 2018), experiences of spinal cord injury (Smith 2013), body anxieties in female exercisers (McGannon and Cameron 2013), overuse injuries in gymnastics (Cavallerio, Wadey, and Wagstaff 2016), and athletes' journeys through the life skills application process (Kendellen and Camiré 2020) – this is the first of its kind to explore the personal and social experiences of hospice-based Tai Chi in people with advanced, incurable disease.

The story presented is based upon the common themes that were derived through data analysis. In crafting these stories, we drew upon on fictional writing techniques outlined by Smith, McGannon, and Williams (2015) to transform the multiple forms of data into a short story. These included: developing plots and characters; writing evocatively and engagingly; dialogue; metaphors; similes; embodiment; and flashbacks and flash-forwards. These techniques were used to develop a story that initially takes readers into the social world of a participant, giving them an intimate insight into their experiences of social death, and then following this by an example of how participating in Tai Chi at the DTU impacted their experiences of social death.

In drawing on the stylistic conventions of CNFs, we aim to create a contextualised, situated, balanced, and relational account of participants' lived experiences of social death, and the impact of Tai Chi as a medium for mitigating its impact (Smith 2013). Accordingly, we hope to produce stories that stir the imaginations of readers, allowing them to become 'caught up in' the tales they read (Frank 2010, p.145) so that they are able to think with and through (as opposed to merely about) participants' experiences (Smith 2013).

A note on reflexivity

During and after fieldwork, [initials removed for peer review] recognised that he was not a 'passive recorder of objective data' (Agar 2008, p.98), and saw the importance of reflecting on the ways in which his personal characteristics and background affected the research process. To this end, [initials removed for peer review] engaged in introsubjective (e.g., inward reflections of how he impacted the research process and vice versa) and intersubjective (e.g., reflections on relationships between researchers and participants) forms of reflexivity (Finlay 2002).

Introspectively, [initials removed for peer review] reflected on how his personal and embodied experiences of being a young, white, able-bodied, and working-class male affected the way in which he understood participants who were much older and iller. Intersubjectively, he reflected on how these personal characteristics affected the ways in which he was positioned in relation to participants, including how it impacted the building of relationships, ethical considerations, and data collection. These reflections were recorded in a reflexive journal that provided a 'springboard for interpretations and more general insight' into the ways through which knowledge was co-constructed throughout this project (Finlay 2002, p.215).

Ethical considerations

Institutional ethical approval was granted from the NHS South Central – Oxford B Research Ethics Committee (REC reference: 16/SC/0133). We understood ethics as a continuous process, in which potentially unexpected methodological and ethical issues may arise during fieldwork, thus adopted a 'Culturally Responsive Relational Reflexive' approach (Lahman et al., 2011) as a guide for responding to 'ethics in practice' (Sparkes & Smith, 2013). This approach foregrounds the appreciation of differences in cultural worldviews and values, and regards ethics as an interpersonal, reflexive process grounded in mutual dignity and respect. In practice, this entailed being attentive to ethical issues including developing trusting relationships with vulnerable people without exploiting these connections, dealing with sensitive subjects, reflecting on potential power imbalances, and ensuring that all aspects of the research process were adaptive to the well-being, safety, and autonomy of participants.

Rigour

We adopted a relativist approach to rigour (Sparkes and Smith 2009). Rather than using rigid, pre-defined lists of criteria to ensure rigour, we used criteria for high quality qualitative research proposed by various scholars (e.g., Smith and Caddick 2012; Sparkes and Smith 2013; Tracy 2010) as a starting point. We then made informed choices in selecting criteria that best aligned with the context, purposes, and methodology of this study. These included: (1) rich rigor, achieved through spending prolonged periods of time immersed within the hospice DTU collecting multiple forms of data to produce rich, layered, and contextualised accounts; (2) sincerity, by using a reflexive journal and working with ‘critical friends’; (3) credibility, by integrating data to produce ‘thick descriptions’ (Geertz 1973); and (4) resonance, through providing thick descriptions of findings and context so that others may transfer these findings to other (similar) settings.

Similarly, we selected the following criteria - based on suggestions by Smith, McGannon, and Williams (2015) - to ensure and judge the rigour of our ethnographic CNFs: (1) aesthetic merit, by creating artistically shaped stories that invites readers into giving interpretive responses; (2) expression of reality, through constructing person-centered, authentic, empathetic, and contextualised accounts of participants’ experiences; (3) evocation and illumination; by emotionally and intellectually illuminating the findings presented in the traditional tales; and (4) meaningful coherence, by showing - as opposed to telling - readers the empirical findings of this study in ways that stimulate novel and evocative understandings.

Findings

The following section first presents participants' personal and social experiences of hospice-based Tai Chi in the form of traditional tales through two themes: (1) fostering social connections and peer support; and (2) the protection of a collective identity. These themes are then represented in an ethnographic CNF entitled 'Moving and being together'.

Fostering social connections and meaningful support

Many participants in this study spoke about how disease-related bodily changes fractured their ability to stay connected to others. As their disease progressed, bodily disintegration worsened, restricting the spaces in which they could operate and the pace at which they could operate within them. For example, physical symptoms (e.g., fatigue, pain, breathlessness, nausea) interrupted participants' ability to easily leave the house and meaningfully engage with others (e.g., going for walks, to the pub, visiting family). Consequently, many participants' social lives/circles progressively shrunk, resulting in feelings of segregation and social isolation. Rachel reflected on how the breathlessness related to her COPD resulted in a form of self-perceived social death because it meant that she 'cut a lot of people off … relationships, things like that. It's just non-existent… Sometimes I might not see anyone for days, so it can be quite lonely really… it's depressing [interview 1]. One participant expanded on how an inability to connect with others and maintain previous social/professional roles perpetuated experiences of self-perceived social death because it removed her sense of purpose/meaning in life:

> I don't have a meaning anymore … I've always been a carer, caring for children and parents, and not having a purpose is very sad. [Christie, interview 1]

Participants reported that participation in Tai Chi encouraged social interactions and brought them closer with others. This was because participation in sessions was perceived as an opportunity in which they were able to experience a sense of social connectedness. Words and phrases such as ‘togetherness’, ‘oneness’, ‘inclusivity’, ‘belonging’, and ‘like a family’ were used to describe these experiences, highlighting the ways in which they seemed to enjoy spending time with other people:

> We’re all entirely different. We’re all from different backgrounds ... I think when you’re in that group doing it [Tai Chi], that’s nice, because it brings you as a unit together. That gentleman over there may not like to talk so you just say good morning, but when you get into the Tai Chi, you’re all doing it together. [Jane, interview 1]

The experience of ‘doing’ Tai Chi together united participants and fostered a sense of belongingness and unity. Tai Chi encouraged participants to connect and interact with each other verbally (laughing, joking, talking) and non-verbally (physical touch, bodily movement, shared mental imagery). Many of these forms of communication were unique to Tai Chi and differed to how participants communicated in other activities within the DTU (e.g., arts/crafts and quizzes). For example, the following observational field note demonstrates how participants were able to meaningfully connect with one another through collective movement and imagery, physical touch, and laughter:

> The physiotherapist guided the participants through a movement where they were to imagine that they were polishing a crystal ball. As Rachel engaged in the movement, Christie turned in her direction with a smile and joked: “clean my shoes while you’re at it”. Rachel gently leaned over and pretended to scrub Christie’s raised foot with the palms of her hand, setting off a chain of laughter that travelled around the circle.

One participant (Judy) commented that these interactions were meaningful because they represented ‘the light and the uplifting that we’re bringing into each other’s lives’ [interview 1].

This was important because participants spoke about how the physical and social impact of their illness made them feel as though they were ‘reliant on other people’ [Christie, interview 1]. However, the social connections and interactions that were shared during Tai Chi were a vehicle through which participants were able to give and receive support to one another in meaningful and purposeful ways. Accordingly, Tai Chi sessions seemed to be socially regenerative by providing social opportunities in which participants could feel of service to others:

> [during Tai Chi] I feel I’m part of something that benefits everybody and it’s nice to feel that you are doing things that will help other people, no matter how small a way. I can’t do what [name of nurse] does, I’m not a nurse, but if in some small way, I mean sometimes you just have to hold somebody’s hand for a few minutes, just to make them feel a wee bit better and it’s just things like that … I just feel that warmth of healing … we seem to respect and care about each other. [Judy, interview 1]

Collectively, the social connections and meaningful support that was experienced by participants during Tai Chi sessions was a way for them to connect and develop/reaffirm bonds that they had made with other people throughout their time at the DTU. By virtue, these forms of interactions helped to restore a sense of community life, and in doing so, alleviate experiences of social isolation and disconnection.

The protection of a collective identity

Many participants commented that living with advanced, incurable disease caused them to experience stigmatisation and a perceived loss of social identity. Debbie spoke about how her paralysis dissolved her role within the family, describing how she had 'lost the feeling and use of my body but people have lost me in a way. [my daughter has] lost her Mom' [interview 1]. Moreover, Christie explained how she experienced other-perceived social death in that she often felt alienated/dismissed by the health system:

> I feel I have been dehumanised by a case of "here's an appointment, go there", "here's a CT scan, go there", and they get you so that your own life doesn't matter to hospitals … they dehumanise you. [interview 1]

This caused many participants to feel ostracised from everyday life because they perceived themselves (or felt that other people perceived them) to be different. Tai Chi was perceived as an activity that brought together participants who had a shared and experiential understanding/respect of what it meant to live with advanced, incurable disease. Accordingly, it represented a time in which they were able to feel normal, ordinary, and accepted:

> In Tai Chi I don't feel as ill. It's nice because I don't go anywhere, unless I go to the hospital or out with my befriender, I don't go anywhere at all except here and *it's nice being able to join in with a group of people and just be ordinary* because the only other places I go are to the hospital or out with my befriender, and it's not the same. [Christie, interview 2, emphasis added]

Tai Chi provided a space within the DTU in which participants were able to experience a sense of closeness with 'other people that are like you' [Jane, informal conversation]. This helped some participants to (re)shape their understandings of what it meant to live with advanced, incurable disease by normalising their illness. Participants' experiences of a collective identity were often referred to as everybody 'being in the same boat':

> [during Tai Chi] we’re all in the same boat, we might not all have the same disease we’re all obviously experiencing it in very different ways, but we’re all in the same boat, we’re all terminally ill and I think it’s that just we’re around, we’re in an environment, protected probably, where we know no-one else is as ill as we are but that’s not what’s important. [Judy, interview 1]

Being part of a group that helped them to feel ordinary and normal was important for many participants. It was especially important to those who felt misunderstood by family and friends who they felt could not fully empathise with what it was like to live with advanced disease. For example, Rachel spoke about how she felt that ‘most people don’t really understand me. They ask me how I am and all that, but they don’t really understand what I’m going through’ [interview 1].

Taking part in Tai Chi at the hospice, however, helped many participants to feel understood in a social context embodied by mutual empathy. Whilst participants did not explicitly ‘talk or mull over [their] problems’ [Jane, informal conversation] during participation, they seemed to appreciate the unspoken, shared solace and protection that it created amongst them:

> it is like somebody putting an arm round you when you walk in, because everybody here’s so nice and everybody’s in the same, or a very similar boat. We’ve all got cancer or carer problems and they’ve been trying to get me into some groups, but you go, and people don’t understand you can just suddenly burst into tears for no sudden reason. But here, everybody understands roughly what you’re going through … you can just be yourself… I feel safe whatever I do. It’s the most wonderful feeling to feel safe and relaxed, comforted, cared for… maybe there’s something safe about being in

> the circle… I think there's no way of escaping, it traps the energy in and the safeness in, within the circle' [Christie, interview 1]

Tai Chi helped participants to feel a sense of belonging within a group that was comprised of other people who empathised with their predicament. It was a shared activity that enabled participants to not be defined by their illness and facilitated a sense of inclusion, equality, understanding, and safety; the types of things that experiences of social death sometimes stripped away from them.

Ethnographic CNF: 'Moving and being together'

> "I've got some good news for you, Christie!" the oncologist beams as he opens the door to his office. Your cancer markers dropped down into the 70's."

In receipt of such good news the oncologist looked perplexed when all that Christie could muster was a brief and fake smile. 'He's totally missed the point,' Christie thinks to herself as she slouches into the back of the chair in the waiting room. In receipt of such news the only thing she could think of was 'yeah? So what?'

As she sits there alone waiting for her taxi, her mind wanders as she reflects on her encounter with the oncologist. She started to question what and who she was. It seems that every time she comes to the hospital she is treated as a walking, talking tumour marker. She understands that the professionals she sees are only trying to help her, but she cannot shrug the overwhelming sense of dehumanisation she feels.

As she arrives back home, no sooner than a twist of the wrist to open her front door, her heart drops. She lethargically pushes the door open and walks into her empty front room where she momentarily stands. She looks onto her mantelpiece to see an old picture of herself surrounded by old friends. Right next to it is another picture of her with her siblings on a holiday when they were young. 'Where are these people now?' she questions herself. She knows that they still live in the same county, yet not once do they bother dropping by and seeing how she is. As these thoughts linger, she continues her all-too-familiar lonesome trek upstairs and into her bedroom where she draws back her bed sheets and slumps her body underneath them. She pulls the cover over herself tightly and hides. This is all Christie wants to do nowadays: hide. Maybe it would be better if she fell asleep and didn't wake up; she doubts anyone would notice anyway.

Later that week at the hospice

Christie slowly makes her way into the main room of the hospice's DTU, taking staggered steps as she bobbles from chair to chair to maintain her balance.

"Morning, Christie!" a volunteer greets her with a friendly and welcoming smile "how are 'ya doing? Can I get you a cuppa?"

In all honesty Christie wasn't doing very well but she already felt uplifted just to be able to get out of the house and see someone. Someone other than the oncologist, or district nurse, or befriender.

"I'll have a cup of tea, please. No sugars." she replies.

"She's sweet enough!" Jane - another person at the DTU - interjects with a cheeky grin.

As Christie takes her seat next to Jane, laughs were shared.

"How have you been?" Jane asks as she takes a sip of her morning coffee.

"Not great if I'm honest. It's been one of those weeks. In and out of hospital like a yoyo." Christie groans.

"You're not on your own there. We've all been there; we all have them."

No more was said about the matter. Christie knew that Jane has been there and done that. Nothing's new or shocking here.

12.20pm

The physiotherapists bounced down into the main day therapy room with their usual smiles and bubbly auras. Over across the far end of the room sat a group of gentlemen sipping tea and conversing with one of the volunteers about the weekend's football results. Debbie and Karen were sat at the opposite end of the room, hands sticky from the glue they were using to make 'Thank You' cards for local fundraisers. People were everywhere and doing all sorts.

"Right then everybody" the physio spoke in an encouraging tone. "Are people up for doing some Tai Chi today?"

A series of nods and smiles followed as most people proclaimed their interest. The volunteers knew what this meant; the weekly re-arranging job. As they cleared out tables from the middle of the room, re-positioned stray Zimmer-frames, and positioned chairs into an inward-facing circular arch, the room transformed from a fragmentation of different activities to a unified formation. As the Tai Chi music started to elevate in volume, everybody sat down in touching distance. Christie realised that in the midst of the chaos, she found herself next to Lee, a recently admitted person who she had not yet had chance to speak with. The physio then starts the first movement:

"Let's start by pretending we are a tree growing at the height of summer."

As she mimics the physio's instructions, Christie moves her arms gracefully towards the ceiling and spreads them outwards. As she turns to her right, she sees Lee's arms mirroring hers as they move in perfect time and harmony. As they extend their arms outward one more time, the tips of their fingers almost touch, but with careful adjustment, Lee avoids collision, bringing his hands back towards himself as they both exchange slight grins.

As everybody continued to glide in and out of movements, imagining waterfalls, sun-kissed beaches, and being a bird spreading its wings on a bright summer’s day, Christie takes a moment to sit back and bask in the warmth of solace and comfort that she felt from being around people all doing the same thing. As she scans the room and see’s everybody joining in with the same movement and imagery, she realises that for the last week the only people she has seen are medical professionals. How nice it is, then, to be surrounded by different people. Actually, these people are very much the same, they’ve all got an incurable disease like her. They understand what she is going through. Everybody’s together for this half an hour, sailing in the same boat. In fact, being able to join in and do these kinds of activities with similar people makes her feel ordinary … less ill. Interrupting her pleasant thoughts, the physio went on to instruct:

> “now imagine you are picking up a light and fluffy cloud on a bright summer’s day. If you see someone else up there with you, give them a smile.”

As Christie twisted her torso, cloud in hand, she caught the eye of the physio and exchanged a warm, healing, and sincere smile. This feeling seemed to reverberate around the circle as smiles bounced from face to face. As she pushed her cloud away, she felt a light bump on her arm.

> “oi you, get off my cloud,” Jane joked as she accidentally knocked her arm into Christie’s.

> “you’d better be careful that the clouds don’t form into a tornado,” Lee chuckled.

As everyone waits for the next movement Christie looks around. Despite the gaps between chairs, it is as though there exists no entrance or exit to the circle. She feels its embrace, almost as though it tightly wraps around her entire being and encases her; protects her; cares for her – 'isn't this a wonderful feeling,' she thinks to herself. So much more warming than the bedsheets under which she usually takes refuge. The whole experience is so positive at a time when she often feels very negative. As the session ends, everybody slowly ascends and makes their way into the dining room where their dinner awaits.

As they pull their chairs out Christie feels somewhat bittersweet. She feels healed by the company she has just experienced. Yet, she knows that as soon as she enters her key into the lock of her front door, her heart will sink again, for she knows what life lies behind it.

Discussion

This is the first study to use focused ethnography to explore the personal and social experiences of people with advanced, incurable disease when participating in hospice-based Tai Chi, specifically focusing on its impact in mitigating experiences of social death. As such, this study contributes to a more thorough and contextualised understanding of the social benefits of Tai Chi in this population by providing unique insights into the socio-cultural and relational processes that underpin engagement. This study also contributes to the application and conceptual understanding of social death in advanced disease, particularly with regards to the value of group-based interventions such as Tai Chi in mitigating its impact.

Discussion of empirical findings

The first theme, 'fostering social connections and meaningful support', demonstrated how taking part in Tai Chi within the social context of hospice day therapy allowed participants to feel connected to, and supported by, others through interacting in meaningful ways. These forms of connection provided a vehicle through which participants were able to alleviate feelings of social isolation/disconnection and open themselves up to giving and receiving support. These findings resonate with other research that has demonstrated the role that Tai

Chi, and physical activity more generally, may play as a source of social connection, belonging, and support in people with advanced, incurable disease (e.g., Gulde, Oldervoll, and Martin 2011; Hägglund, Boman, and Brännström 2018; Paltiel et al. 2009; Yeh et al. 2016; Turner et al. 2016). Accordingly, they complement the notion that group-based physical activity serves an important role in helping people with advanced, incurable disease cope with difficult life challenges and suffering.

By adopting a focused ethnography, these findings also extend our understandings of how experiences of Tai Chi are situated within the socio-cultural context of hospice day care. That is, within the hospice culture, Tai Chi appeared to represent a sub-cultural activity in which participants socially interacted in different ways compared to other activities (Wolcott 2008). The ways in which these forms of communication worked to facilitate a sense of connectedness and support may be understood through the notion 'moving sociability' (Doughty 2013) in which participants seemed to use the ebbs and flows of bodily movement and visualisations during Tai Chi to 'significantly relax social norms around communication, thus make these fleeting moments of proximity enjoyable and valued as a form of companionship' (Doughty 2013, p.142). Connecting with each other through physical movement seemed to be particularly powerful because it allowed participants to work collectively in simultaneously buffering the impact that physical disintegration and social disconnection had in contributing to their experiences of social death.

The second theme, 'the protection of a collective identity', showed how Tai Chi brought participants - who had a common understanding of advanced disease - together under a shared identity. Participants appeared to value these shared understandings because they helped to normalise their illness and provided a sense of emotional safety and care. This was particularly important considering that many participants' experiences of social death were characterised by a feeling that others around them often struggled to empathise with what it meant to live with an advanced, incurable disease. This finding is similar to previous literature that has demonstrated the value of Tai Chi and gym-based exercises in providing an opportunity for people with advanced disease to use mutual understandings of illness to reach out, empathise with, and share experiences with each other (Yeh et al. 2016; Malcolm et al. 2016).

The findings of this study are novel because they demonstrate the underlying mechanisms used by participants to develop and use collective identities to alleviate their own and others' experiences of social death during Tai Chi. In the context of chronic and advanced disease, collective identities refers to connecting with others who have similar illness experiences and using shared understandings of their own vulnerabilities to reach out to, care for, and improve the well-being of other people who are suffering in similar ways (Lehardy and Fowers 2018). This type of collective identity closely aligns with the concept of self-compassion; a central aspect of Tai Chi philosophy (Wayne and Fuerst 2013). Self-compassion is defined as 'being touched by and open to one's own suffering … so that one's experience is seen as part of the larger human experience' (Neff 2003, p.86-87). Thus, this finding underscores the uniqueness of Tai Chi as an activity within hospice day therapy in creating compassionate groups in which people with advanced disease can develop positive collective identities that may be used as a form of emotional care/protection whilst helping to normalise illness experiences.

In using Tai Chi to develop collective identities and foster social connections and meaningful support, participants seemed to engage in the 'craftwork of illness' (Frank 2003). This represented a self-conscious process in which participants collectively used their minds and bodies in creative, practical, embodied, and social ways to craft different ways of understanding their illness and alleviate experiences of social death. As part of the craftwork of illness, Frank (2003) suggests that people may latch onto different 'narrative templates' (stories used to make sense of what it means to live with advanced illness). One such narrative template our findings suggest participants 'latched onto', was that of 'extensive responsibility' (Frank 2003). This is described as:

> [for] those who have suffered most, something more is then required. Suffering does not buy us out of further service because we have, as the phrase goes, suffered enough already … Suffering is the call to and preparation for works of further service. (Frank 2003, p.249)

By 'further service', Frank describes illness as an ethical and moral process in which, despite advanced disease, participants were still able to respond to the social suffering of others 'with a self-consciousness of their own vulnerability' (Frank 2003, p.428). That is, many participants' stories suggested that they experienced (at least some elements of) social death – albeit in differing ways, to differing degrees, and in different contexts. Whilst for some participants social death was self-perceived, for others it was other-perceived (Kalish 1968). Tai Chi seemed to be a way in which participants could enact stories of 'extensive responsibility' by allowing them to tune into - rather than avoid or isolate themselves from – the commonality between their own and others' experiences of suffering. By opening themselves up to giving (and receiving) support from others in these ways, they were able to engender a desire to heal and connect in ways that alleviated feelings of social death.

Accordingly, hospice-based Tai Chi seemed to be a unique context in which participants perceived themselves, and were perceived by others to be, 'socially active' compared to other contexts (Borgstrom 2017, p.7). This demonstrates how hospices play a key part in specialist palliative care in helping to alleviate experiences of social death in people with advanced, incurable disease, and how group-based activities such as Tai Chi may be considered an important part of palliative care's holistic approach in managing peoples' social and emotional needs.

Methodological reflections

The originality and impact of this study is also present in its use of ethnographic CNF's. We believe that their use contributes to, and supports, contemporary methodological discussions on how we may seek to conduct high quality qualitative research (see: Bazeley 2009; Brinkmann 2015; Chamberlain et al. 2011; Gough and Lyons 2016). These discussions have advocated for qualitative research to be treated as a 'craft' (Brinkmann 2015) in which pluralism, creativity, and diversity of methods are embraced. By using ethnographic CNFs, we were able to do this by working towards the type of 'creative thinking, theorising, imagination, patience [that] are all essential to high quality research and thus to the production of new and different knowledge' (Gough and Lyons 2016, p.239). This is because CNFs possess various strengths that enable researchers and readers opportunities to understand the research questions of this study in ways that conventional forms of representation do not.

First, CNFs enabled us to weave together numerous theories/concepts (social death, collective identities, craftwork of illness) with study findings. In showing theory in and through a story, we have used CNFs to deepen theoretical knowledge and understanding regarding social death in people with advanced illness (Smith 2013). Second, CNFs allowed us to create a well-balanced, empathetic, and person-centred piece that allows for multiple understandings regarding Tai Chi participation in the context of advanced disease (Smith, McGannon, and Williams 2015). This is because they draw on literary techniques that humanise participants' lives and evocatively *show* - therefore allowing readers to inhabit - participants' situated and relational experiences of social death and how Tai Chi helped to mitigate its impact (Smith, McGannon, and Williams 2015). Third, because they draw on engaging stylistic conventions that resist academic jargon, CNFs are conducive to disseminating research to wide audiences in accessible ways and achieving different types of impact that are not always possible with conventional forms of representation. This is because stories have the power to resonate at a personal and emotional level and invite critical and interpretive reflection from multiple audiences (Smith 2013). One way in which these stories may be impactful is through acting as a form of 'narrative care' (Smith 2013, p.136) for others with advanced disease by providing them with a source of comfort and solidarity, and showing them that they are not alone, but are part of a community connected to others who are experiencing advanced illness in similar ways.

Limitations and strengths

In contextualising the findings of this study, it is important to highlight some limitations. First, we are conscious that this study focuses exclusively on the positives of hospice-based Tai Chi in mitigating social death for people with advanced, incurable disease. However, we are wary not to conform to the 'exercise is medicine' narrative in uncritically arguing that Tai Chi can alleviate social death in all people suffering from advanced illness (Williams et al. 2018). We are mindful that the stories presented in this study are limited in that they rely on the experiences of people who were (for the most part) enthusiastic about Tai Chi. Second, the palliative population is diverse and service users who access palliative day therapy are usually physically fitter/less deteriorated than many other people with advanced disease. Therefore, the ways in which people who are further on in their disease trajectory may use Tai Chi to alleviate experiences of social death remains unexplored. Thirdly, participants were not involved in the construction of CNFs, nor were theirs or other audiences' reflections on these stories gathered. Future work using CNFs may benefit from considering participatory methodologies that seek to involve multiple stakeholders in the co-construction of stories, and seek their responses to them, so that more confident claims regarding the generalisability of findings can be made.

These limitations, however, are not to be interpreted as perpetuating outdated ideas that qualitative research cannot be generalised due to limited sample size/diversity. In fact, we argue that a strength of this paper is that using ethnographic CNFs to represent findings in evocative, accessible, and rich ways enhances the potential of this work to be generalised in different ways and to different people. Drawing on work by Smith (2018), *naturalistic generalisations* may be made by people with advanced, incurable disease who find that the accounts provided of social death and the impact of Tai Chi resonates with their own personal experiences. *Analytical generalisations* may also be made through demonstrating the applicability and value of social death as a concept through which to understand lived experiences of advanced, incurable disease and how hospice-based Tai Chi may mitigate experiences of social death in this population.

Conclusion

Previous research has demonstrated the physical and psychological health benefits of Tai Chi for people with advanced, incurable disease. This study drew on focused ethnographic methodology to illustrate the social and relational value of hospice-based Tai Chi in people with a range of advanced, incurable diseases, specifically focusing on the role that it plays in mitigating the impact of social death. Participation in Tai Chi provides an opportunity for people with advanced disease to alleviate experiences of social death through engaging in the ‘craftwork of illness’. This is by fostering social connections and meaningful support, and creating the protection of a collective identity with others. These findings demonstrate the value of group-based Tai Chi as a non-pharmacological intervention that complements a holistic and person-centred approach to palliative care. It also demonstrates the value of using ethnographic CNFs in this context to evocatively represent lived experiences of illness and Tai Chi by weaving together theories and findings in a form that is accessible beyond academic audiences.

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