Physical activity and quality of life in palliative care: An ethnographic study exploring patients' experiences of and views on participation in a hospice-based Tai-Chi programme

by

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In memory of Neil, day therapy is not the same without you.

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Keep Right On!

Abstract

Living with a terminal illness presents multifaceted adversities that can undermine various domains of an individual's well-being. In addressing these issues, palliative care adopts a holistic and multidisciplinary approach which seeks to improve the quality of life of patients. Mindful movement therapies are one way in which the goals of palliative care may be achieved. However, the ways through which patients with terminal illnesses view and experience these types of interventions within the context of hospice care is unclear. Thus, the aims of this thesis were to utilise a focused ethnography to explore: (a) how participation in hospice-based Tai Chi impacted patients' perceptions of quality of life; and (b) patients' views on Tai Chi, including the perceived barriers and facilitators that they experienced in relation to their participation. 19 patients who were diagnosed with an advanced, incurable illness were recruited to this study. Data was collected using multiple methods, including: semi-structured interviews, participant observations, and informal conversations. It was analysed using a thematic framework approach. With regards to the study's first aim, three themes captured how taking part in Tai Chi impacted participants' perceptions of their quality of life, including: (a) the pleasures of mind-body respite; (b) social engagements; and (c) case studies of outliers. With regards to the study's second aim, five themes were constructed which demonstrated how the barriers and facilitators to taking part in hospice-based Tai Chi fell at multiple, inter-related levels of engagement (e.g., intrapersonal, interpersonal, and community). These included: (a) physical limitations; (b) enjoyable and worthwhile activity; (c) group practice; (d) autonomy and choice; and (e) supervision by professionals. Based on these findings, empirical, practical, and methodological implications are highlighted which make the case for the integration of Tai Chi (and other mindful movement/physical activity interventions) as an integral facet of rehabilitative palliative care practice as a means to improve quality of life in patients with life-limiting illnesses. Recommendations for health-care professionals working in this context on how to design and deliver Tai Chi programmes in clinical practice are discussed. Central to this discussion – and something that is laced throughout the findings of this thesis – is an emphasis on the importance of the cultural context of the hospice day therapy unit in which participants' views and experiences of Tai Chi were located.

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Preface

(all extracts taken from the book "Mortality" by Christopher Hitchens (2012))

"The thing about Stage Four is that there is no such thing as Stage Five." These are the words of Christopher Hitchens as he reflects on his experiences with advanced, incurable oesophageal cancer; a battle which agonisingly stripped him of the abilities that had made him so infamous. The irony was, whilst so many people egged him on to "fight" and "battle" his cancer, he felt that he was fighting and battling nobody; it was the cancer that was waging war on him. "The image of the ardent soldier or revolutionary is the very last one that will occur to you," he said, "you feel swamped with passivity and impotence: dissolving in powerlessness like a sugar lump in water."

This imposed war was one that threatened his very essence; his identity. Writing and speaking were not just what made him his living, rather, they were what made him. For Hitchens, the ability to write and speak were ways to create memories, bring tears and laughter, move people, and to lose these faculties was a death in itself. "It's true," he wrote:

> I feel my personality and identity dissolving as I contemplate dead hands and the loss of the transmission belts that connect me to writing and thinking… deprivation of the ability to speak is more like an attack of impotence, or the amputation of part of the personality… but one finds that every passing day represents more and more relentlessly subtracted from less and less.

This was an attack which took him into new, unfamiliar, and uncomfortable territories. He calls this new territory "Tumourtown". A land which had a lingua franca and gestures of its own. Having complete strangers sinking their fingers deep into your neck and then telling you that the cancer has spread to your lymph nodes was a given in Tumourtown. In particular, the word "metastasized" was one that stood out to him. It was a way of describing how this "blind emotionless alien" was sadistically colonising and burrowing itself into his body.

The assault on his body that this "blind emotionless alien" had waged was one that he spoke about not being prepared for – in fact, it was one that he *couldn't possibly* be prepared for. For Hitchens, it suddenly became "no fun to appreciate to the full truth of the materialistic proposition that I don't *have* a body, I *am* a *body.*" By

this it was quite obvious what he meant. The physicality of navigating the "lacerating days and nights" of terminal illness and its associated treatment-related side effects was a physically and mentally gruelling experience which left him feeling "upsettingly denatured":

> it's the snickering [of the cancer] that gets me down. On a much too regular basis, the disease serves me up with a teasing special of the day, or a flavour of the month. It might be random sores and ulcers, on the tongue or in the mouth. Or why not a touch of peripheral neuropathy, involving numb and chilly feet? Daily existence becomes a babyish thing … on the less good days, I feel like that wooden-legged piglet belonging to a sadistically sentimental family that could bear to eat him only a chunk at a time. Except that cancer isn't so … considerate. Most despond-inducing and alarming of all, so far, was the moment when my voice suddenly rose to a childish (or perhaps piglet-like) squeak. It began to register all over the place, from a gruff to a husky whisper to a papery, plaintive beat. And at times it threatened to disappear altogether.

For Hitchens, there was an element of wagering that pervaded his illness experience; the "oncology bargain" he called it. That is, in return for treatment which may have offered him a few more months or years of life, he had to be prepared to give over some things to the cancer: his hair, and his ability to concentrate, digest, and taste. But these were feeble compared to the pain and fatigue that the treatment imposed:

> I do remember lying there and looking down at my naked torso, which was covered almost from throat to navel by a vivid red radiation rash. This was the product of month-long bombardment with protons which had burned away all of the cancer in my clavicular and patracheal nodes, as well as the original tumour in the oesophagus … to say the rash hurt would be pointless. The struggle is to convey the way that it hurt on the inside. I lay for days on end, trying in vain to postpone the moment when I would have to swallow. Every time I did swallow, a hellish tide of pain would flow up my throat, culminating in what felt like a mule kick in the small of my back… Nothing at all could have readied or steadied me for this thing that seemed to scorn painkillers and to attack me in my core.

All of this had left him feeling physically weak. But his physical body alone was not enough prey for the alien. It attacked his hopes, aspirations, and dreams. Hitchens spoke about how he had real plans for the future and felt as though he had worked hard enough throughout his career to revel in these. Would he live long enough to see his children and niece get married? Would he ever get to visit his hometown in England again? Would he be able to go out with his friends in town on Friday? As a torturer would torment their victim, it seemed as though the cancer had turned around and sniggered: "no". Along with the daily flesh it devoured, so too had the cancer taken away his future desires, and this depressed him somewhat. Yet, in the midst of this palaver, a modicum of hope always remained. Without ever deluding himself of his prospects of survival, he still clung onto the possibility of some sort of miraculous cure, responding to "every bit of clinical and statistical good news with radical, childlike hope", for this would've allowed him to fulfil the plans he had for the future.

Whilst faced with such existential issues, Hitchens was determined not to project his worries and fears onto family or friends. His philosophy was very much one of: "I'll do the facing of hard facts. Don't you be doing it too." The afterword of Hitchens' collection of essays about his experiences of advanced, oesophageal cancer is written by Carol Blur, his wife. What is so striking about her raw and emotional account is the way that Hitchens' disease so obviously transcended him as an individual. It was as though the alien intruder had bought her, and other close friends and family, front-row seats to spectate his progressive decline. His wife was the one who had to witness him throwing up into bins whilst enjoying a day out at a museum, coughing up blood late in the night during a hospital stay, and grieve his loss as she stumbled across his notes from unfinished projects.

The reason for prefacing this thesis with such a story is because it sets a precedent for one of the main underlying themes that runs throughout this thesis: living with advanced, incurable disease. With this in mind, this thesis aims to take the reader into the lives of participants with advanced, incurable disease and provide an account of how mindful movement, specifically Tai Chi, affected their lived and situated experiences of quality of life. In one sense, Hitchens himself accurately sums one of the implicit aims of this thesis when he wrote: "the most satisfying compliment a reader can pay is to tell me that he or she feels personally addressed."

Should this be achieved, the stories of participants' experiences of Tai Chi should resonate with and move readers on an empirical, intellectual, personal, emotional, ethical, and practical level.

Part 1

Introduction, Methods, and Context.

Chapters 1 to 5 comprise the first part of this thesis. This section includes an introduction, literature review, outline of the conceptual frameworks, methods and methodology used, and accounts of participants' lived experiences of advanced, incurable disease and the cultural context of the hospice's day therapy unit. Collectively, these chapters provide readers with the information that is required to contextualise the empirical findings that are presented in part 2.

Chapter 1: Introduction

1.0. Description of the Problem

Advanced, incurable disease represents a stage of the disease trajectory whereby the bodies of patients no longer responds to curative treatment (Schofield, Carey, & Aranda, 2006; Twycross, 2003). Because diseases at this point of illness resist cure, most patients living with advanced, progressive diseases have a limited life expectancy of around 6 months to a year (Kaasa & Loge, 2003). Upon receiving news of such a prognosis, the multiple fears (e.g., of worsening symptoms, physical suffering, loneliness, burdening others, and impending death) and losses (e.g., of physical functioning, independence, security and vulnerability, and the future) presents patients with multifaceted adversities which can have a profoundly negative impact on their physical, psychological, social, and existential domains of well-being (McLeod & Clarke, 2007; McKechnie, MacLeod, & Keeling, 2007; Parkes, 1998; Schofield et al., 2006). Thus, the needs of patients within this population are multiple, complex, and can change overtime as their disease becomes more progressive. Since the consequences of living with advanced, incurable disease are troublesome for patients and their families, in managing their condition, the focus of healthcare delineates from disease-modifying treatments to palliative and hospice care (Spencer & Daniels, 1998; Twycross, 2003).

The central aim of palliative and hospice care is to help patients "live until they die" (Saunders, 2001, p. 42) by attending to their physical, psychosocial, and existential needs (Jocham, Dassen, Widdershoven, & Halfens, 2006; Santiago-Palma & Payne, 2001; Twycross, 2003). This is achieved through adopting a holistic, multidisciplinary (i.e., medical, nursing, psychosocial, cultural, and spiritual care), and patient-centred ethos/approach, which aims to ameliorate patients' and their families quality of life (Twycross, 2003). Both pharmacological (i.e., conventional medicine) and non-pharmacological (i.e., complementary and alternative medicine such as aromatherapy, reflexology, massage, and relaxation) therapies are widely used to prevent and relieve suffering such as pain, fatigue, and anxiety, alongside reducing hospital stays (Ernst, 2001; Harding et al., 2005; Higginson et al., 2003; Higginson & Evans, 2010; Kavalieratos et al., 2016).

Despite the holistic care that is provided to patients, Clark (2002, p.906) recognises that a preoccupation with "evidence-based" models and medical advancements has resulted in the "creeping medicalisation" of palliative care. This is exemplified by the proliferation in medical subspecialties within the area (e.g., palliative medicine, oncology, neurology, and cardiology), as well as the routine use of medical guidelines to evaluate best practice (Floriani & Schramm, 2012). In turn, this has meant that an increased emphasis is placed on interventions (e.g., drugs and therapies) that often treat the physical concerns of patients (e.g., pain and symptom management), at the expense of their psychosocial and spiritual needs (Chochinov, 2006; Clark, 2002). As mentioned above, however, living with an incurable, progressive disease has implications far beyond the physical dimension of well-being. Whilst palliative medicine plays an important role in improving patients' quality of life through relieving pain and suffering associated with physical symptoms and treatment side effects, holistic therapies that treat more than the physical body should not be overlooked.

Mindful movement therapies represent a unique and increasingly popular approach to addressing the multidimensional needs of this population by seeking to integrate the mind, body, and spirit (Elkins, Fisher, & Johnson, 2010; Klein, 2017). Tai Chi exemplifies one such mind-body therapy which is based on the concept of Qigong. Rooted in traditional Chinese medicine, Tai Chi involves the integration of rhythmic movements, breathing regulation, and mindful practices, which can enhance the flow of "vital energy" (Qi) throughout the body in ways that are said to maintain and restore health and well-being (Klein, 2017). Preliminary evidence has demonstrated the promise of Tai Chi for helping patients improve their day-to-day functioning and quality of life. However, this research has mainly used methods that are disembodied (i.e., numerical outcomes that orient the body as an *object* of scrutiny) and dualistic (i.e., quality of life measures which fragment physical, psychosocial, and existential issues). Furthermore, participants' experiences of Tai Chi and quality of life have been de-contextualised from the socio-cultural environments in which they are embedded. As an evidence-base, therefore, much of our understandings of the role that Tai Chi may play on patients' perceptions of quality of life are detached from the complexities of participants' lived and situated experiences of illness (Sparkes & Smith, 2014). Consequently, they are unable to

provide a holistic portrayal of how Tai Chi impacts multiple areas of quality of life that are important to individuals in this population (Kaasa & Loge, 2003). What's more, given the overreliance on quantitative methods, research in this area has done little to illuminate the mechanisms underlying the efficacy of Tai Chi, or how patients subjectively experience its role with regards to coping with the multiple fears and losses that commonly pervade advanced illness experiences (Sparkes & Smith, 2014). The present study addresses these gaps in the literature.

1.1. Thesis Overview

This thesis contains 10 chapters. In **chapter 2** I start with a review of the relevant literature that pertains to this thesis. This includes discussions surrounding various concepts and theories that are included throughout this write-up, alongside the relevant work that has already been conducted in this area. **Chapter 3** further supplements this by providing an introduction to the conceptual frameworks on which this project was built. In **chapter 4** I then turn to how I conducted this PhD project. This includes a description and discussion of the methods and methodology that were used in guiding the collection, analysis, and representation of data. In this chapter I also discuss how I navigated the various ethical issues that were pertinent to conducting qualitative research in a palliative care context and the criteria through which readers may wish to judge the quality of this project by. I end chapter 4 with a discussion of why, in contrast to most ethnographic practice, I chose not to leave the setting in which I conducted my fieldwork once data collection had ended. In **chapter 5** I then seek to "set the scene" by providing the reader with a contextual backdrop through which the empirical results of this thesis can be understood. This is through using data collected during my time in the field to provide an account of participants' lived experiences of terminal illness, alongside a cultural portrait of the day therapy unit in which this PhD project was conducted. In **chapters 6-9** I present the empirical findings of this project. **Chapter 6** focuses on how taking part in a hospice-based Tai Chi program impacted participants' perceptions of their quality of life through introducing the theme: "the pleasures of mind-body respite." This shows the ways in which Tai Chi was able to help participants deal with the physical and psychosocial adversities that their illnesses inflicted through grounding their minds and bodies in pleasurable and peaceful sensations that were occurring in the present moment. **Chapter 7** continues the focus on Tai Chi and quality of life through the theme of

"social engagements". This shows how Tai Chi was a platform through which participants could engage in the "craftwork of illness" (Frank, 2003) by providing an activity in which they could connect with and reach out towards other patients as they worked as a group in dealing with their illnesses. **Chapter 8** is then used to juxtapose the main themes presented through chapters 6-7 by presenting case studies of "outliers". These highlight the messy, complex, and sometimes negative experiences that some participants had whilst taking part in hospice-based Tai Chi. In **chapter 9** the focus of this thesis turns to participants' views on, and the barriers and facilitators that they faced in relation to, taking part in the hospice-based Tai Chi program. This draws on a social-ecological model to demonstrate the various ways in which Tai Chi was experienced at multiple levels of engagement. Finally, **Chapter 10** brings the thesis to a close. This is through reflecting on how this work contributes to the literature empirically, practically, and methodologically. I use this chapter to make various practical recommendations with regards to the role that Tai Chi may play at improving quality of life in a hospice setting and how we may best seek to design and implement such programs.

1.2. Situating Myself in the Research Project: A Note on Reflexivity

In ethnography (and qualitative research more generally), researchers are intimately entangled within their research projects. This means that our gender, values, beliefs, personalities, socio-cultural backgrounds (and so on) affect the ways in which we conduct research as well as the lenses through which we understand, analyse, and interpret data (Agar, 2008; Sparkes & Smith, 2014). Taking into consideration researcher subjectivity, the notion of neutral, value-free knowledge in qualitative research is unattainable (Sparkes & Smith, 2014; Wolcott, 2008); in the words of Agar (2008, p.98): "you do not go into the field as a passive recorder of objective data". However, the main foe of qualitative research is not that we bring biases and assumptions to our research projects, rather, it is when they go unchallenged and subsequently form prejudices that distort our data (Wolcott, 2005). Because of this it is important that we are able to recognise, and be transparent about, the ways in which we as researchers impact our research projects (Fetterman, 2010; Wolcott, 2008).

This may be achieved through a process of "reflexivity". Finlay (2002a, p. 532) define reflexivity as a:

> thoughtful, conscious self-awareness. Reflexive analysis in research encompasses continual evaluation of subjective responses, intersubjective dynamics, and the research process itself. It involves a shift in our understanding of data collection from something objective that is accomplished through detached scrutiny of "what I know and how I know it" to recognizing how we actively construct our knowledge.

Implicit in the above definition is that numerous types of reflexivity exist, each of which are dependent on the theoretical and methodological traditions that are used within a study (Finlay 2002a; Finlay 2002b).This project was grounded in social constructionism (see chapter 4.2), therefore the meanings and interpretations of participants' views and experiences of Tai Chi were negotiated and co-created within the social context of the hospice. With this in mind, I engaged in a combination of introspective and intersubjective forms of reflexivity (Finlay, 2002b).

During introspective reflections I turned inwardly to think about the ways in which I was impacting the research process and how it was affecting me. This included the raw emotional experiences, discomfort, and privileges that were associated with researching and volunteering within a hospice context, alongside how my prior background and experiences affected the ways through which I made sense of data. What's more, in making these types of reflections, Turner (2000) argued that it is important that we reflect upon ourselves as embodied and socially situated subjects within our research. Thus, within my introspective reflections I sought to self-examine how my own embodied and corporeal presence and experiences within the context of the day therapy unit influenced the research process and my understanding/interpretations of research questions. Examples of such are provided in critical reflections boxes 5 and 7.

Intersubjective reflections extended to being actively conscious of how the researcher-researched relationship (or the "self-in-relation-to-others") affected the situated and negotiated nature of how data was formed, understood, and interpreted (Finlay, 2002a; Finlay 2002b). It also included how I reflected on the ethical issues that arose throughout the duration of the project (Finlay, 2002a; Finlay 2002b). This

included reflections on the following: (a) how my role and rapport with participants influenced the types of relationships that were developed and how this affected the co-construction of knowledge; (b) were these relationships ethical (i.e., was I transparent with regards to the boundaries of my role where risks of exploitation, or "seduction" (Wolcott, 2005), were minimised?); and (c) was I appropriately preserving the autonomy and confidentiality of patients throughout the project?

These different types of reflections were not simply an act of lip-service to being reflexive, rather, they were a genuine attempt to use my experiential and intersubjective experiences in the field as a "springboard for interpretations and more general insight" of the ways through which knowledge was co-constructed throughout this project (Finlay, 2002b, p. 215). Nevertheless, for all of the epistemological and ontological opportunities that it offers, there are also potential pitfalls and perils of engaging in reflexive analysis. Finlay (2002b, p. 212) likens reflexivity to "entering uncertain terrain where solid ground can all too easily give way to swamp and mire". By this she means that during reflexive journeys there is the danger of entering an infinite regress of self-analysis which privileges the researcher and overshadows participants (Finlay, 2002b). In seeking to negotiate the swamp of reflexivity, therefore, I aimed to balance reflexive introspection with intersubjective reflections through maintaining primary focus on understanding participants' experiences and the texts that were being produced. I only sought to turn inwardly when it presented a genuine opportunity to facilitate richer insight into the research process and data analysis/interpretation (Finlay, 2002a; Finlay, 2002b).

I made the aforementioned types of reflections throughout all stages of the research process (e.g., prior to, during, and after fieldwork) and recorded them in a reflexive journal. Throughout the thesis, I invite the reader into my reflexive world through using entries from my reflexive journal in the form of critical reflection boxes. These run parallel to the main text and aim to make transparent the ways through which I interpreted and co-constructed data, as well as negotiated the various personal, methodological, practical, and ethical challenges that were associated with this project. In supplementing this, before taking you on the research journey that my PhD entailed, I lay bare what I feel to be relevant aspects of my own personal background to make clear to the reader the socio-cultural baggage and prior

experiences that I bring to this project. In doing so, I seek to "position" myself as a researcher within the boundaries of this study.

I am a 24-year-old, white male from a working-class background. In part, this inevitably formed the backdrop through which I saw, analysed, and made sense of the contents of this research project and how I felt I was able to navigate intersubjective relationships with participants. For example, my socio-cultural background is quite obvious through the fairly strong "Brummie" accent that I embody. I felt as though this was somewhat of a novelty that patients in the hospice (perhaps subconsciously) warmed to; I was sort of perceived as "the young lad with the funny accent who was here to help us". In this way, from the first day I entered the hospice there was a sense that my presence was seen as unthreatening and that patients could trust me with their experiences and stories. That said, I was aware that aside from similarities in socio-cultural backgrounds, I inhabited a very, very different embodied world to the participants in this study.

Specifically, I am a young, able-bodied, and healthy male who was trying to understand the experiences of participants who were considerably older and in different physical health than myself. To date, I have been fortunate enough to evade first-hand contact with serious illness and perhaps even more fortunate in not experiencing what it is like to see close friends and family members progressively deteriorate in uncompromising ways. Consequently, at the start of this project I was filled with a profound sense of "not getting" what death and dying really entailed. As I navigated this project, therefore, I constantly reflected on the question: "how could I ever fully understand the participants' lived experiences of quality of life and Tai Chi when I have never felt what it is like to have a terminal illness?" Whilst I make no attempt in pretending that I ever fully answered (or could answer) this question, I went to extra lengths in attempting to immerse myself in the business of death and dying. This included volunteering at the day therapy unit in which this project was conducted before, during, and after data collection (April 2016-present). Through doing so I hoped to learn from patients by adopting the "student-child-apprentice learning role of [an] ethnographer" (Agar, 2008, p. 242) so that I was in a better position to enhance the authenticity, sincerity, and credibility of accounts and analyses provided throughout this thesis.

Another factor which I feel important to comment on is how my educational background in Sports and Exercise Sciences formed a lens through which I made sense of participants' views and experiences of Tai Chi. Upon reflection, this is a background which was firmly lodged in the "exercise is medicine" paradigm; a neoliberal and biomedical perspective which comprises of an over-simplistic, homogenised, and individualistic evidence-base that maintains exercise is akin to a miracle pill that if taken acts as a "cure for all ills" (Williams, Hunt, Papathomas, & Smith, p.451). Indeed, I realised that at the start of my project this was subconsciously reflected in my own beliefs. However, palliative care is a unique context and the notion of exercise being a "cure" does not lend itself well to understanding what mindful movement can mean to patients with terminal illnesses. Thus, whilst I have no doubt of the curative (and other positive physical) benefits that exercise may have on other populations, throughout this thesis I made a continuous and conscious effort to remain critically reflexive of the different meanings that it could take on for patients in this population.

Now that I have set the scene through describing the problem on which this thesis is built and positioning myself within the research project, in all of its subjectivity and partialness, I welcome the reader into reading my PhD thesis.

Chapter 2: Literature Review

2.0. Overview

The content included within this PhD thesis traverses across a broad range of fields, concepts, and theories. These include terminal illness, quality of life, well-being, palliative and hospice care, physical activity, embodiment, and mindful-movement therapies. Therefore, this chapter aims to provide the reader with a discussion of the pertinent literature that relates to this project as a means to provide them with a contextual background through which the rest of this thesis may be understood.

2.1. The Need for Palliative Care

By 2040, the number of people requiring palliative care services in the UK is estimated to rise between 25%-47% (Etkind et al., 2017). This is for various reasons. One of these is that there is expected to be sizeable increases in the incidence, prevalence, and mortality of chronic, progressive illnesses (Etkind et al., 2017). By 2040, the number of people expected to die each year is expected to rise by 25.4% (Etkind et al., 2017), with a large proportion of this number expected to suffer from life-limiting diseases such as cancer and dementia (Calanzani, Higginson, & Gomes, 2013a; Etkind et al., 2017). Another factor contributing to the projected rise in the need for palliative care is an ageing population. Specifically, within the UK, the number of people aged 85 or above is expected to increase from 1.4 million people in 2010 to 3.5 million in 2035 and people falling into this age range are expected to account for half the deaths across the UK (Calanzani et al., 2013a). Given the improvements in detection and treatment of chronic and advanced diseases, many of these individuals will be expected to live longer with a life-limiting illness (Ferrel, Ferrell, Ahn, & Tran 1994; Stewart & Wild, 2014). For this reason, there are various initiatives currently underway aiming to address the inequities that exist in this area of health (e.g., Calanzani et al., 2013a; Calanzani, Koffman, & Higginson, 2013b; Hospice UK, 2017a, Hospice UK, 2017b). These include improving the provision and access of hospice care for patients with non-cancer diagnoses, non-malignant diseases, and those from BAME backgrounds. If successful, this will further add to the need for palliative care in the coming years, thus:

that hospices will need to change is beyond doubt. The scale of the challenge ahead is dramatic and will require hospices to significantly increase the extent and scope of end of life services. The opportunity and the test for hospices will be whether they can develop the greater reach, accessibility and complexity of service required to meet these needs. (Calanzani et al., 2013, p. 2)

The ability of hospices being able to respond to these challenges is of great importance considering the detriments to quality of life that is associated with living with advanced incurable disease.

2.2. Living with Advanced, Incurable Disease

Advanced, incurable disease encompasses a wide range of progressive, life-threatening illnesses and can include patients who suffer from cancer, chronic heart failure, chronic obstructive pulmonary disorder (COPD), and neurological disorders such as Parkinson's, Multiple Sclerosis, and Motor Neurone Disease. Because serious illness has the power to change everything about a person's life, it has the potential to be an all-consuming experience. These changes span physical, psychosocial, and existential domains of well-being (see figure 1) and can significantly undermine the ability of individuals to live life in self-fulfilled, meaningful, and comfortable ways (Ek & Ternestedt, 2008). This next section will review the literature on the topic of living with advanced, incurable disease to demonstrate the multifaceted adversities and suffering that is commonly faced by patients in this population.
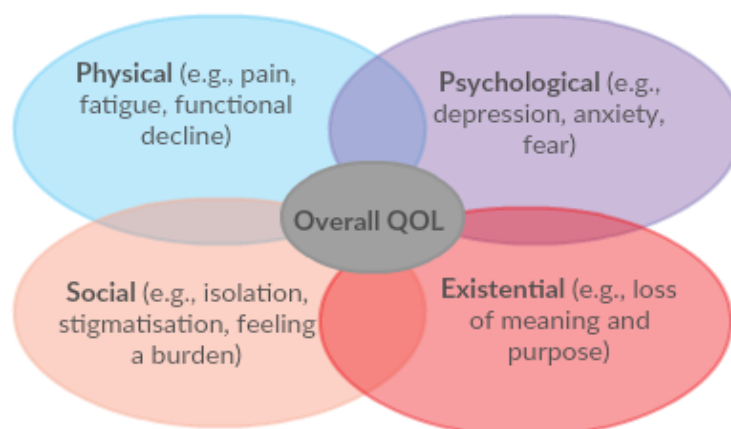
Figure 1: *The most common advanced, incurable disease symptoms*

2.2.1. Physical distress.

A wealth of qualitative and quantitative research has demonstrated the physical adversities that are associated with the various disease types that comprise the palliative population. These have included patients with advanced cancer (e.g., Donnelly & Walsh, 1995; Luoma & Hakamies-Blomqvist, 2004; Murray et al., 2007; Schofield et al., 2006; Teunissen et al., 2007), heart failure (e.g., Alpert, Smith, Hummel, & Hummel, 2017; Bekelman et al., 2009; Boyd et al., 2004; Murray et al., 2007), COPD (e.g., Garrdio et al., 2006; Seamark, Blake, Seamark, & Halpin, 2004; Seamark, Seamark, & Halpin, 2007; Zamzam, Azab, El Wahsh, Ragab, & Allam, 2012), and neurological disorders (e.g., Benito-Leon, Morales, Rivera-Navarro, & Mitchell, 2003; Rahman, Griffin, Quinn, & Jahanshahi, 2008). Though these diseases affect patients in different ways and to different magnitudes, there is commonality with regards to prevalence of disease- and treatment-related physical symptoms that are reported by patients. For example, a systematic review consisting of 44 studies (including 25,074 participants), identified fatigue, pain, lack of energy, weakness, and appetite loss as the symptoms most commonly reported by patients with a variety of incurable cancers (e.g., brain, lung, breast, prostate etc.) (Teunissen et al., 2007). These physical symptoms (alongside others such as breathlessness and oedema) have also been demonstrated in systematic reviews on patients with COPD (e.g., Seamark et al., 2007) and heart failure (e.g., LeMond & Allen, 2011; Zambroski, Moser, Bhat, & Ziegler, 2005). Whilst quantitative studies and reviews have been useful in providing an understanding of the types, prevalence, and severity of symptoms experienced by patients diagnosed with a wide range of advanced, incurable diseases, qualitative research has given rich insight into the complex ways that these illnesses can impact patients' lived experiences of physical well-being.

For example, in her ethnographic work on the dying process, Lawton (2000) provides a rich and embodied account of the physical distress that is experienced by advanced cancer patients. In it she describes how the "irreversible" and "non-negotiable" physical deterioration that is caused by the body eating away at its own flesh culminates in patients feeling "taken over" by their disease, thus unable to act in autonomous and independent ways. In another qualitative piece of work exploring the embodied illness experiences of 19 patients with incurable cancer, Reeve, Lloyd-

Williams, Payne, and Dowrick (2010) demonstrate how the physical effects of disease and treatments fractured and overwhelmed the lives of participants. For example, the physical side-effects of radiotherapy (e.g., lacerating pain, severe depletion of energy, and inability to eat) dominated and controlled the ways in which patients were able to function, often reducing them to physical and emotional exhaustion.

In addition to the debilitative effects that symptoms such as fatigue, pain, and physical deterioration can impart on an individual's physical well-being, there is a wealth of evidence that shows how living with progressive, incurable disease can disrupt patients' psychological functioning.

2.2.2. Psychological distress.

The literature shows that it is common for patients with advanced, incurable disease to become anxious, depressed, and experience feelings of hopelessness (Boston, Bruce, & Schreiber, 2011; Chochinov, 2006; Färkkilä et al., 2014; Kolva, Rosenfeld, Pessin, Breitbart, & Brescia, 2011; LeMond & Allen, 2011; McLeod & Clarke, 2007; Seamark et al., 2007; Smith, Gomm, & Dickens, 2003; Spencer, Nilsson, Wright, Pirl, & Prigerson, 2010; Stewart, Teno, Patrick, & Lynn, 1999; Wilson et al., 2007; Zhang, Nilsson, & Prigerson, 2012). The prevalence of these symptoms are often more common than physical concerns (Chochinov, 2006) and patients who suffer from these types of psychological distress can be up to 4 times more likely to have a desire for hastened death (Breitbart et al., 2000). Because the impact of psychological suffering can be so profound, much research has attempted to explore the mechanisms through which detriments to psychological well-being manifests itself in patients with advanced, incurable disease.

In doing so, many studies have demonstrated the relationship between progressive physical decline and psychological distress (e.g., Chochinov, 2006; Seamark et al., 2007; Smith et al., 2003; Tang, Aaronson, & Forbes, 2004), highlighting the intimate connection between the mind and body during illness. These have shown that physical decline and discomfort (e.g., pain, reduced strength, functioning, and breathlessness) act as constant reminders of disease progression and that time is limited. For example, utilising an interpretative phenomenological approach to explore 10 COPD patients' perceptions of their illness, Seamark et al.

(2007) demonstrated how the shortness of breath caused by progressive dyspnoea - which led to feelings of claustrophobia and coughing fits - instilled a sense of fear and anxiety in patients. The fear and anxiety of the unpredictability of one's body often becomes more pronounced as patients' disease and physical deterioration progresses (Chochinov, 2006). Furthermore, detriments to psychological well-being can also exacerbate and re-activate the physical symptoms that patients with advanced, incurable disease face, causing a vicious cycle in which bodily-based anxieties (e.g., fear of decline, or a hyper-focus on breathing patterns) can offset physical decline (e.g., breathlessness and fatigue) and vice versa (Chochinov, 2006).

Aside from the impact that physical deterioration has on psychological well-being, terminal illness represents a time in patients' lives which is fraught with a multitude of uncertainties and (real and imagined) losses. These may be in relation to the fear of cancer spreading, physical deterioration, financial issues, or the impending separation from, and impact of death and dying on, family and friends (McKechnie et al., 2007; Rainbird, Perkins, Sanson-Fisher, Rolfe, & Anseline, 2009; Smith et al., 2003; Stewart et al., 1999; Thompson et al., 2009). For example, McKechnie et al. (2007) demonstrated the lived experiences of uncertainty and loss in patients with advanced carcinoma. Faced with the combination of uncertainties surrounding the efficacy of treatment options and intense feelings of loss (e.g., of health, family, community, creativity, and hopes and aspirations), patients were overwhelmed by a sense of their worlds collapsing around them. Whilst physical and psychological suffering undermines patients' quality of life in very personal and embodied ways, advanced, incurable disease transcends the individual and can fracture their social lives and relationships with others.

2.2.3. Social distress.

Regardless of disease type, the literature demonstrates that detriments to social well-being commonly manifest themselves in the form of feeling isolated, perceiving oneself as a burden, stigmatisation, feeling unable to fulfil social roles, and the straining of relationships (Chochinov, 2006; Guthrie, Hill, & Muers, 2011; Johnson, Sulmasy, & Nolan, 2007; McCaffrey, Bradley, Ratcliffe, & Currow, 2016; McKechnie et al., 2007; Murray et al., 2007; Rahman et al., 2008). For example, in a

systematic review and synthesis including 24 qualitative studies on patients with a wide range of advanced diagnoses (e.g., cancer, heart failure, COPD, and AIDS), McCaffrey et al. (2016) highlighted the importance that patients placed on maintaining social roles and relationships with their friends and family. However, as their disease progressed, and they became unable to engage in everyday activities, a sense of being dependant on, and a burden to, others made them nervous for the future and undermined their perceptions of quality of life.

As well as causing them to become dependent on others, the process of physical decline has also been found to shrink patients' social worlds (Ek & Ternestedt, 2008; Ettem, Derksen, & van Leeuwen, 2010; Murray et al., 2007; Rokach, Matalon, Safarov, & Bercovitch, 2007; Seamark et al., 2004). As their illness confines them to their houses and creates a sense of stigmatisation, patients commonly feel excluded and sequestered from participation in everyday life and are left feeling socially and existentially isolated (Ek & Ternestedt, 2008; McKechnie et al., 2007). Estrangement and the loss of interpersonal relationships often occur because of the frustrations of feeling that friends and family members cannot empathise with their lived experiences of illness. In consequence, patients commonly experience what Lawton (2000) refers to as a "social death" long before their physical deaths. This is characterised by a loss of personhood/self that is experienced as patients progressively lose the ability to act autonomously and their relationships with others dissolve (Lawton, 2000).

Alongside the detriments to quality of life that can occur through perceiving oneself as a burden to others and experiencing various forms of isolation, life-limiting illnesses also present adversities that can undermine an individual's existential well-being.

2.2.4. Existential distress.

During advanced stages of illness, it is not uncommon for individuals to experience various forms of existential suffering (e.g., uselessness, hopelessness, despair, and desire for hastened death) as they reflect on, and struggle with, profound existential questions surrounding their mortality and meaning/purpose in life (Edwards, Pang, Shiu, & Chan, 2010; McClain, Rosenfeld, & Breitbart, 2003; Murray, Kendall, Boyd, Worth & Benton, 2004; Schofield et al., 2006). Indeed, there

is a wealth of literature which shows the clear link between existential suffering and poorer levels of well-being at the end-of-life. For example, when life becomes bereft of meaning and purpose, deteriorations in psychological (e.g., anxiety and depression) and social (e.g., relationship/communication problems and isolation) domains of well-being can occur (Boston et al., 2011; Chochinov, 2006; McClain et al., 2003; Murray et al., 2007; Schofield et al., 2006). This type of distress can be just as crippling as the physical suffering, thus even when physical symptoms are well-controlled, patients may still experience suffering through their inability to find meaning in their illness experience (Stewart et al., 1999). Because of this, it has been suggested that existential issues may be the fundamental underpinning of poor psychological health in those with advanced, incurable disease (Kaasa & Loge, 2003; McClain et al., 2003).

There are numerous reasons to explain why patients can experience spiritual distress near the end of life. One proposition is that the inability to find meaning or hope in life can result in a loss of interest in, and desire for, living (Chochinov, 2006). Kissane, Clarke, and Street (2001) go further to demonstrate how the amalgamation of losses in hope, meaning, and purpose can demoralise patients to the point of despair. In what they label as "demoralisation syndrome", the sense of hopelessness that arises from individuals feeling as though they are held captive by their disease can result in a state of existential distress in which they become pessimistic, negative, and desire a hastened death.

This section has demonstrated how the physical, psychosocial, and existential distress that is associated with advanced, incurable disease can disrupt and significantly undermine patients' quality of life. Accordingly, it has touched upon the concepts of quality of life, health-related quality of life, and well-being. The literature surrounding these concepts, however, is abundant in complexities and debates. Therefore, the next sub-chapter offers an expansion of what these concepts entail and how they relate to a palliative care setting.

2.3. Quality of Life and Health-Related Quality of Life

Quality of life (QOL) is a broad concept which, in general, refers to "evaluations of the "goodness" of one's life overall, and the goodness of all of the various domains that make up one's life" (Lox, Martin-Ginis, & Petruzzello, 2010, p.400). The use of the term "QOL" became popular during the 1960's as a result of U.S. domestic policy which dedicated itself to advancing the population's QOL through social programs such as education, housing, community development, health, and welfare (Day & Jankey, 1996; Mandzuk & McMillan, 2005). With its initial development being centred on social issues, the concept was originally applied within the field of sociology (Mandzuk & McMillan, 2005). Since then, the use of QOL as an outcome measure has been utilised in a diverse array of arenas (e.g., economics, politics, education, health, technology, and environment), thus its precise definition depends on the context in which it is used (King, 2012; Roop, Payne, & Vallerand, 2012). For example, QOL in economics often focuses on gross domestic product, education, and levels of employment, whereas in health-care it solely includes domains of an individual's life that are associated with their health (Lox et al., 2010; Karimi & Brazier, 2016).

Because of the proliferation in the disciplines in which it has been used and defined, QOL is a term which has resisted consensual and universal definition (Haas, 1999). Adding to the difficulty in defining what we mean by QOL is that it has often been mistaken for, and used synonymously with, other closely related concepts such as well-being, happiness, life satisfaction, and functional and health status (Ferrans, 2005; Haas, 1999; King, 2012; Meeberg, 1993). Thus, its amorphous and often confusing nature has led to some authors abandoning its definition altogether (King, 2012). However, this is problematic as it hinders the ability to make comparisons between studies and develop comprehensive theories that can inform practice and improve patient outcomes (Ferrans, 2005; Roop et al., 2012). Therefore, in attempting to improve the conceptual clarity and definition of QOL, concept analyses (e.g., Haas, 1999; Mandzuk & McMillan, 2005; Meeberg, 1993) have been conducted. Based on her concept analysis of 65 research and theoretical articles, Haas (1999, p.733) provides the following five defining attributes which pertain to QOL:

(1) QOL is an evaluation of an individual's current life circumstances,

(2) QOL is multidimensional in nature,

(3) QOL is value based and dynamic,

(4) QOL comprises subjective and/or objective indicators, and

(5) QOL is most reliably measured by subjective indicators by persons capable of self-evaluation.

Against the backdrop of these defining attributes, as a general concept, the World Health Organisation (WHOQOL Group 1995, p.1404) define QOL as:

> an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment.

The above definition, however, is broad. Therefore, whilst QOL may include people's evaluations of wide-ranging concepts related to cultural, political, and environmental aspects of their lives (e.g., income, education, employment etc.), within the contexts of health and medicine the term "health-related quality of life" (HRQOL) is often used. This may be seen as a sub-component of QOL which focuses more narrowly on individuals' evaluations of their lives in relation to their health (Kaasa & Loge, 2003; Lox et al., 2010; Karimi & Brazier, 2016; Ferrans, 2005; Roop et al., 2012). In health-related research, the definitions and conceptualisations of HRQOL have been multitudinous (Fayers & Machin, 2007; Ferrans, 2005; Karimi & Brazier, 2016). For clarity, then, it may be more productive to focus on what scholars agree, as opposed to disagree on, in relation to the concept. As presented in Haas' (1999) defining attributes of QOL above, the unifying consensuses on HRQOL are that it is a multidimensional, subjective, and dynamic construct (Bakas et al., 2012; Cella, 1994; Fayers & Machin 2007; Haas, 1999; King, 2012; Roop et al., 2012).

As a multidimensional construct, HRQOL is comprised of different "domains" or "dimensions" of what contributes to a "good" or "bad" life in regard to one's health (Cella, 1994; Fayers & Machin, 2007; Ferrans, 2005). Whilst there has been much debate over what domains should be included in HRQOL measures and how we should weight each domains importance (Donnelly, 2000), most scholars agree that HRQOL can be split into five dimensions. These include: physical (e.g., strength, energy, ability to perform activities of daily living, and self-care); psychological (e.g., anxiety, depression, and fear); social (e.g., interpersonal relationships with friends, family, colleagues, and the community); somatic (e.g., disease symptoms and side-effects of treatment); and spiritual (e.g., instilling life with meaning and purpose) wellbeing (King, 2012). Although often described as single entities, the different domains of HRQOL should not be viewed as discrete but rather as synergistic and interdependent, whereby fluctuations in one domain can impact an individual's perceptions in others (Ferrell & Dow, 1997). For example, improvements in physical well-being (e.g., reductions in pain and fatigue) can have knock-on effects on an individual's perception of their psychological well-being (e.g., elevated positive affect) and vice versa.

Furthermore, to accept that HRQOL is a subjective construct is to appreciate that it means different things to different people, therefore what comprises a "good" QOL can only be understood from the perspective of the individual (Cella, 1994). Twycross (2003, p.5) captures this notion perfectly when he wrote that "quality of life is what a person says it is". Although the majority of definitions of QOL accept and are based on the notion that it can only be understood through the subjective judgements and evaluations of individuals themselves, some scholars (e.g., Cummins, 2005; Felce & Perry, 1995; Lox et al., 2010) have argued that objective indications should be included. Objective conceptualisations of QOL deny the necessity of an individual's interpretation of their life circumstances and hold that there exists external and "objective" factors which contribute to making people's lives "quality", regardless of their personal judgements or attitudes (Bognar, 2010; Brown et al., 2004). In this way, if certain objective factors are fulfilled, an individual can be deemed as having a good QOL (Brown et al., 2004; Molyneux, 2007). Within health-related research, these objective features have often included outcomes such as the sizes of an individual's tumour, blood pressure, levels of haemoglobin, adverse

reactions, symptom relief, cost-effectiveness, amongst many others (Ferrans, 2005; O'Boyle & Waldron, 1997).

The assumption that a person's QOL is a result of the fulfilment of objectively measurable outcomes, such as those described above, is born out of a biomedical model which considers health and disease as objectively and directly measurable states (O'Boyle & Waldron, 1997). However, drawing on the work of Sumner (1996), Molyneux (2007) critiques these objective notions on two fronts. Firstly, they fail to meet the criterion of "formality". In other words, they provide lists of features that are supposed to comprise an individual's QOL yet fail to explain why some features make the list and others do not. Secondly, they are also inadequate in accounting for the "intuitive subjectivity of welfare" (Molyneux, 2007 p.569), that is, a person's own attitudes and beliefs on what it means for their life to be going well. By overlooking its inherent subjectivity, Ferrans (2005) argues that objective conceptualisations of QOL are somewhat illusionary, giving the example of nausea and vomiting to illustrate her point. That is, whilst we may be able to count the amount of times somebody gets or feels sick, we can never make objective judgements on the intensity or severity of these episodes. This is because even if two individuals experience the same amount of sickness and nausea, one individual may appraise it in such a way that significantly undermines various aspects of their QOL, whereas in the other, no change is experienced. Thus, even when an individual's QOL appears to be going well when assessed by "objective" health criteria, they may still appraise their lives as going badly and vice versa (Molyneux, 2007).

In response to debate over whether QOL represents a subjective or objective construct, various hybrid theories and conceptualisations (e.g., Cummins, 2005; Haas, 1999; Mandzuk & McMillan, 2005; Meeberg, 1993) have been offered. These posit that QOL is made up of *both* an individual's subjective appraisal of their lives and the fulfillment of objective indicators. Under this notion, a good QOL is said to be obtained if a person subjectively appraises their life to be going well as well as objective features (e.g., low tumor markers, blood pressure, symptom relief etc.) being present (Molyneux, 2007). The problem with hybrid theories, however, is that - as seen in the examples above - they collapse into subjectivism. As Molyneux (2007, p. 568) argues:

The two categories, objective and subjective, are mutually exclusive—if a theory of welfare happens to include both subjective and objective components (as is often the case), then this hybrid theory would be classed as subjective, as it contains a positive (or negative) attitude as an essential component of welfare.

Thus, for all the talk of HRQOL being both subjective and objective, these two positions are philosophically incommensurable and when one looks closely, it is an individual's subjective evaluation of their health which is the most reliable measure of HRQOL. This, then, supports the suggestion that to understand HRQOL, one must consider not only the values that underpin what it means to an individual, but also their appraisals of how dysfunction and deterioration may impact one's perception of it (Cella, 1994; Stewart et al., 1999). With an individual's appraisal and meanings attached to their HRQOL considered, it is unsurprising that it is treated as a dynamic concept (Cella, 1994). This is often understood through the concept of "response shifts" which demonstrate how a person's values and standards of what makes a good HRQOL may change over time and contexts (Haase & Braden, 2012).

Because it embraces many of the same values (e.g., it is a multi-dimensional, subjective, and dynamic construct) the concept of well-being bares similarity to that of QOL (Pinto, Fumincelli, Mazzo, Caldeira, & Martins, 2017).

2.3.1 Well-being.

Camfield and Skevington (2008) go as far as to say that recent definitions of well-being are "virtually synonymous" with the World Health Organisation's definition of QOL presented in the previous chapter in that they both acknowledge the importance of value judgements, life satisfaction, and the importance of the mind and body. However, rather than being used as surrogate terms, Pinto et al. (2017) argue that because QOL focuses more broadly on satisfaction with life generally and well-being more narrowly on psycho-spiritual aspects of an individual's life, the two should be treated as related (yet different) concepts which share similar attributes. In this way, well-being is a significant indicator, as opposed to the same thing as, QOL (Olthuis & Dekkers, 2005).

As a concept, then, well-being is often identified with the "prudential value" (i.e. the inner and outer events that impact how *good* a person's life is) of an

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individual's life (Olthuis & Dekkers, 2005). Implicit within the notions of prudential value and well-being is the focus on how and why individuals experience their lives in *positive* (as opposed to negative) ways (Diener, 1984). Despite the importance many philosophers placed on positive human functioning, up until the 1980's, the field of psychology devoted considerably more attention to researching the causes, consequences, and amelioration of unhappiness and suffering (Diener, 1984; Ryan & Deci, 2001; Ryff, 1989a, 1989b). In doing so, the promotion of well-being and growth was overshadowed and neglected (Ryan & Deci, 2001). However, mainly due to the seminal work of Diener (1984) and Ryff (1989a) on subjective and psychological well-being respectively, there has been a proliferation of interest in, and research on, the factors which facilitate and thwart an individual's ability to experience their lives in positive ways.

Diener's and Ryff's conceptualisations of well-being represents two contrasting, yet often overlapping, schools of thought: hedonism and eudemonism. Whilst the former equivocates well-being with happiness and pleasure, the latter proposes that well-being entails much more than happiness. That is, it is the result of the actualisation of human potentials (Ryan & Deci, 2001). It is to these two paradigms of well-being to which I now turn.

2.3.1.1. The hedonic approach.

The hedonistic approach to well-being has its roots in early Greek philosophy where Aristippus proposed that in order to live a life imbued with happiness, one should maximise the amount of pleasure and minimize the amount of pain that they experience (Ryan & Deci, 2001). From a hedonist perspective, therefore, well-being is synonymous with happiness and pleasure and is represented through the concept of subjective well-being (SWB) (Deci & Ryan, 2008; Diener, 2000; Ryan & Deci, 2001). The subjective nature of SWB is based on the notion that because each person owns a unique set of expectations, values, and previous experiences, they will often react differently to the same situation (Diener, Suh, Lucas, & Smith, 1999). Thus, SWB prioritises an individuals' personal perspective of their well-being through permitting them to evaluate *for themselves* what instils their life with value and makes it worthwhile living (Diener, 1999, 2000).

Ryan and Deci (2001) recognise that the hedonistic conception of SWB has been expressed in various forms, from a relatively narrow focus on bodily pleasures, to a broader focus which extends beyond physical hedonism and incorporates an individual's appetites and self-interests. Most psychologists adopt the latter conceptualisation which integrates the pleasures and preferences of the mind and body (Ryan & Deci, 2001). This latter conceptualisation is represented by Diener et al.'s (1999) description of SWB which includes affective and cognitive evaluations of an individual's life.

The components that make up SWB, therefore, are: affect, life satisfaction, and domain satisfaction. Affect represents a person's affective evaluation of their emotions and moods and can be split into two sub-categories: (a) pleasant affect (e.g., the experience of pleasant emotions such as joy, elation, pride, affection, happiness, and ecstasy) and; (b) negative affect (e.g., the experience of unpleasant emotions such as guilt and shame, sadness, anxiety, stress, depression, and envy). In addition to affect, the second component of SWB includes an individual's cognitive evaluation of their life satisfaction (e.g., overall judgements on the "goodness" of one's life). The final component is domain satisfaction, which is the satisfaction that an individual has within various contexts of their lives (e.g., work, family, self, and finances). It follows from this that a state of SWB is characterised by high levels of pleasant affect, low levels of unpleasant affect, and an evaluation that one is satisfied with their life in various domains (Diener, 2000; Deci & Ryan, 2008).

The hedonic approach to SWB, however, is only one way through which philosophers and psychologists have conceptualised well-being.

2.3.1.2. The eudaimonic approach.

Despite its popularity and the proliferation of research that has been conducted on the hedonic conception of SWB, many philosophers, particularly Aristotle, have belittled the equivocation of hedonic happiness with well-being, arguing that the pursuit of pleasure and desires were "vulgar ideals" (Deci & Ryan, 2008; Ryan & Deci, 2001). He argued that, just because an individual experiences subjective happiness in the form of high levels of pleasant affect and satisfaction in the short term, it does not mean that they lead good lives or experience psychological wellness (Deci & Ryan, 2008). In fact, some go further as to argue that

pursuing activities which satisfy our subjective desires can be harmful to the growth that is essential in experiencing authentic forms of well-being (e.g., Fromm, 1981). Proposing an alternative conception of well-being, then, Aristotle argued that authentic happiness arises when an individual lives a virtuous life, that is, engages in activities that are worth doing (Ryan & Deci, 2001). In this way, well-being, and happiness is not viewed as a subjective state, but rather as a normative standard against which the "goodness" of people's lives may be judged (Diener, 1984).

Psychologists who have adopted Aristotelian thought take on what Waterman (1993) has called the "eudaimonic" conception of well-being. This is the notion that in order to experience well-being an individual must live in harmony with their "true self", or "*daimon*" (Waterman, 1993). An individual's daimon refers to the "potentialities" that:

> are shared by all humans by virtue of our common specieshood and those unique potentials that distinguish each individual from all others. The daimon is an ideal in the sense of being an excellence, a perfection toward which one strives and, hence, it can give meaning and direction to one's life. Efforts to live in accordance with the daimon, to realize those potentials (self-realization), give rise to a condition termed eudaimonia (Waterman, 1993, p. 678).

Implicit within eudaimonic approaches to well-being resides the thought of various humanistic psychologists (e.g., Allport, 1961; Jung, 1993; Maslow, 1968; Rogers, 1961) who propose that all humans, regardless of the culture in which they reside, have a universal and innate tendency to grow, or "*self-actualise*". Through integrating the work of the above theorists, Ryff (1989a; 1989b) proposed a different model of well-being – psychological well-being (PWB) – which was based on eudaimonic thought. This challenged notions of SWB through proposing that well-being was not merely the attainment of pleasure and avoidance of pain, but the actualisation of an individual's true potential (Ryan & Deci, 2001). According to Ryff (1989a; 1989b), PWB consists of six components that need to be fulfilled if one is to attain optimum psychological function:

1. *Self-acceptance.* This is a fundamental feature of mental health and self-actualisation and refers to an individual pertaining positive attitudes towards themselves.

2. *Positive relations with others.* The importance of forming warm and trusting relationships with others, in which one can experience and provide love, empathy, and affection.

3. *Autonomy.* The capacity of an individual to resist the constraining features of enculturation, thus function in self-determined and independent ways.

4. *Environmental mastery.* An individual's ability to choose, construct, or creatively change complex environments so that they match their physical and psychological needs.

5. *Purpose in life.* Feeling as though one has a sense of direction, which instils their lives with purpose and meaning.

6. *Personal growth.* Optimum psychological functioning is experienced when, in addition to fulfilling the components above, one is able to develop and actualise their potential so that they can continually grow and develop as a person.

The aforementioned types of well-being are theorised to be located within an individual's mind and body. However, thinkers within the field of health geography (e.g., Andrews & Moon, 2005; Andrews et al., 2014; Gesler, 1992; Kearns, 1993) have also emphasised the importance of space and place with regards to well-being.

2.3.1.3. Space, place, and well-being.

Through adopting a holistic, social ecological perspective (see chapter 3.2), health geographers appreciate how experiences of well-being are often *part of* the social, cultural, and physical environments in which individuals are embedded (Andrew & Moon, 2005; Kearns, 1993). That is, the relationships between people and elements of their environment has a profound impact on a person's sense of well-being (Kearns, 1993). Accordingly, health geographers remind us that "place matters" to health and health care; that where individuals are cared for, live, work,

socialize, and how they use and experience their environments, have far-reaching implications (Andrews et al., 2014, p.211). This is because places "do things"; they possess various "basic functions" (Andrew et al., 2014, p.210), or "opportunity structures" (Andrew & Moon, 2005, p.57) (e.g., features of the environment such as the quality of buildings or soundscapes), that can impact how people think and feel within them, with some contexts being more conducive to fostering feelings of well-being than others (Andrew & Moon, 2005). In accounting for the dynamic relationship between space/place and well-being, the field of health geography has given rise to various concepts including affective environments (Andrews et al., 2014) and therapeutic landscapes (Gesler, 1992).

In their concept of "affective environments", Andrews et al. (2014) argue that feelings of well-being arise through "affect" (i.e., pre-reflective physical experiences). From this perspective, experiences of well-being are an intimate entanglement of (or interaction between) embodied sensory perceptions and our environments; well-being arises "initially as an energy and intensity through the physical interaction of human bodies and non-human objects, and [are] experienced as a feeling state" (Andrews et al., 2014, p.211). That is, whilst environments provide various cues (e.g., different soundscapes, smells, lighting, textures etc.) that may impact how we experience well-being, these are rapidly transmitted directly into the lived body and are fundamentally experienced at pre-cognitive, visceral levels (Andrews et al., 2014). It is only after this transmission occurs that affective feeling states are registered within our conscious awareness, manifesting themselves as different types of feelings and emotions. In these ways, well-being may be understood as *part of an affective environment,* that is, features of the environment act on people in and through their senses which, in turn, result in different types of affective feeling states. The "energies" that affective feelings states carry has important implications with regards to well-being. Drawing on the work of Deleuze (1988), Andrews et al. (2014, p.217) note that this is because:

> negative affection (described as 'sadness affect') acts like a form of poisoning that weighs an individual down and reduces their capacity to operate physically and mentally, positive affection (described as 'joy affect') acts as a nutrition that energizes an individual, carries them forwards and increases their capacity to operate.

Accordingly, affective environments that (either naturally or through design and manipulation) can provide opportunities to experience positive states of well-being are more likely to be valued and sought out by individuals than those that do not (Andrews et al., 2014).

Another concept within the field of health geography that notes the intimate interaction that environments have with a person's perception of their well-being is therapeutic landscapes (Gesler, 1992). In recognising the importance of space and place, this concept reveals how intra/interpersonal, environmental, and societal processes interact with each other in creating landscapes that possess healing and therapeutic qualities (Gesler, 1992). Thus, they are best 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). In these ways, therapeutic landscapes are an amalgamation of physically built environments as well as products of the human mind and material circumstances (Gesler, 1992). These may include physical features (e.g., fresh air, scenery, room layout), a positive sense of place (e.g., the positive meanings, felt value, and sense of comfort/security), socio-cultural values (e.g., how people act, or feel able to act), and symbolic aspects (e.g., how cultural values are expressed) that are located within certain environments (Gesler, 1992). Therapeutic landscapes may be present in a variety of healthcare settings, including palliative care, and are useful ways of exploring the complex ways through which an individual's experiences of well-being may be affected by the environment that they are in (Andrews & Moon, 2005). For example, Moore et al. (2013) found that hospice day care centres may act as therapeutic landscapes in the ways that they represent a safe haven in which patients feel a sense of "at-homeness", being cared for, and close to others. The physical, symbolic, and social environment of day care was able to "heal" patients through sheltering them from perpetual feelings of fear and dread, thus re-orientating them in ways that helped to restore a sense of order and meaning in their lives. It is to space and place of palliative and hospice care that I now turn.

2.4. Palliative and Hospice Care

Much of the philosophy and development of palliative and hospice care can be traced back to the pioneering post-war work of Dame Cicely Saunders. Hospices

as we know them today were built on the foundations laid by Saunders and her colleagues in 1967, where in South London they opened the first modern hospice: St Christopher's. Central to its endeavour was to create a centre of excellence for caring for those with terminal illnesses through the amalgamation of clinical care, research, and teaching. The effectiveness and success of St Christopher's meant that it became the gold standard for treating individuals towards the end of their lives, and as such, stimulated a domino effect in the rapid development of hospice care in the UK and across the world (Clark, 2007). In the midst of its proliferation, the underlying principle of palliative care has remained. This principle is best captured through the notion of what Saunders labelled "total pain". That is, the appreciation that physical, mental, social, and emotional suffering are intertwined, each pertaining the capacity to affect one another in ways that can cause considerable distress (Clark 1999, 2007).

Considering that patients' illnesses are not curable, palliative care aims to address the complex entanglement of patients' physical, psychosocial, and existential needs through a focus on QOL. This is captured in The World Health Organisation's (2017) definition of palliative care as:

> an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

In striving to achieve its aims, palliative care adopts a holistic, multidisciplinary, and patient-centred approach, which facilitates the acceptance of death as a natural process whilst simultaneously ameliorating patients' QOL throughout the entire palliative care journey (i.e., from diagnosis through to end-of-life) (Dixon, King, Matosevic, Clark, & Knapp 2015; Jocham et al., 2006; Santiago-Palma & Payne, 2001; Twycross, 2003). It does this through utilising a diverse team of trained health-care professionals (e.g., physio/occupational therapists, doctors, nurses, family and bereavement support specialists etc.) and volunteers who strive towards placing patients at the centre of the care process. They do so through

working towards helping patients manage symptoms and achieve their personal goals and aspirations, within inpatient, outpatient/day case, and community settings.

Whilst they share the same principles and ethos, Dixon et al. (2015) notes that palliative care is often confused with other types of care that may be given to patients with life-limiting diseases (e.g., end-of-life, hospice, and supportive care). For clarity, the differences between these types of care are outlined in table 1.

Table 1: The differences between palliative, end-of-life, hospice, and supportive care. Based on definitions provided by Dixon et al. (2015)

Type of care	Definition
End-of-life	Care provided to patients within the last phase of life so that they can die with dignity. This typically ranges between a year and the last weeks/days of a person's life and extends to including bereavement care for friends and family members.
Hospice	These are the places in which palliative and end-of-life care are given. They usually represent local charities who provide care within in-patient units and the community.
Supportive	Has the same aims as palliative care but is provided to patients who have serious illnesses where a cure is thought to be possible.

Within palliative, hospice, and end-of-life care, a patient's perception of their QOL is often used to identify whether or not their care needs are being met. Assessing QOL can also be a handy prognostic tool for assessing overall survival and efficacy of interventions (Benito-Leon et al., 2003; Lox et al., 2010; Meier & Brawley, 2011; Stevens, Martin, & White, 2011; You, Habiba, Chang, Rodriguez-bigas, & Skibber, 2011). Because of the salience of QOL as an outcome measure within a palliative context, Kaasa and Loge (2003) note the importance of conceptualising it in ways that are reflective of the goals of palliative care services and the common needs of patients who access it. Consequently, within this context, QOL is commonly represented by the following domains: (a) physical wellbeing; (b) psychological wellbeing; (c) social wellbeing; and (d) spiritual wellbeing (Ferrell,

2005; Jocham et al., 2006; Kaasa & Loge, 2003; Twycross, 2003). Whilst these domains are often used to conceptualise QOL in "healthy" populations and earlier stages of the disease trajectory, their definitions within a palliative care context differs (Stewart et al., 1999).

Physical well-being is largely concerned with an individual's functional ability, and their experiences of disease-related symptoms that are pertinent to the different types of diagnoses commonly found in palliative care (e.g., pain, fatigue, dyspnoea, and nausea). Psychological well-being refers to factors that contribute to psychological distress such as anxiety, depression, fear, and worry. What's more, because the dying process is often characterised by the sense that one lacks control (whether this be in relation to the general physical process of dying, decisions over treatment, or the scheduling of appointments) (Singer, Martin, & Kelner, 1999; Stewart et al., 1999), maintaining a sense of autonomy and control during this time is also something that is important to psychological well-being (Stewart et al., 1999). Social well-being is concerned with perceptions of being a burden, changing roles, and relationships with others. Spiritual well-being has often been used synonymously with existential well-being, which can cause some confusion over its definition. However, Chochinov (2006) recognised that in the context of palliative care, distinguishing between them is less vital than understanding their common ground. That is, they refer to the universal desire to instil life with purpose, meaning, and hope. One facet of palliative care's multidisciplinary approach which seeks to improve these domains of patients' QOL is palliative rehabilitation.

2.4.1 Rehabilitative palliative care.

As a concept, rehabilitation within the context of life-limiting illness is often misunderstood. This is because the term "rehabilitation" is mostly associated with the recovery and restoration of physical functions, expectations that are unrealistic in a context where patients are undergoing irreversible and progressive physical decline (Hospice UK, 2015; Leslie, Sandsund, & Roe, 2014). Only construing rehabilitation as restorative, however, presents a narrow conception of the other meanings that it may take on in a palliative care context. Indeed, in their publication emphasising the importance of rehabilitative palliative care in the 21st century, Hospice UK (2015) open up its definition in defining it as a paradigm which:

aims to optimise people's function and wellbeing and to enable them to live as independently and fully as possible, with choice and autonomy, within the limitations of advancing illness. It is an approach that empowers people to adapt to their new state of being with dignity and provides an active support system to help them anticipate and cope constructively with losses resulting from deteriorating health. Rehabilitative Palliative Care supports people to live fully until they die. (Hospice UK, 2015, p.2).

As implied in the above definition, therefore, the goals of rehabilitative palliative care are (more often than not) adaptive (i.e., adjusting to progressive disease-related decline) as opposed to restorative (i.e., re-establishing previous levels of functioning). Its goals revolve around improving patients' QOL through buffering disease-related decline in ways that allow them to remain physically functional and active for as long possible (Hospice UK, 2015; Javier & Montagnini, 2011). The specific goals of rehabilitative palliative care are multiple and are based on work by Dietz (1969, 1981) who proposed four levels of rehabilitation, including: restorative; preventative; supportive; and palliative (Hospice UK, 2015; Javier & Montagnini, 2011; Leslie et al., 2014). Within palliative care settings these relate to the following:

- *Restorative:* Returning patients back to initial levels of functioning (e.g., re-gaining the ability to balance and walk after a fall).

- *Preventative:* Aiming to prevent and buffer disease and treatment-related decline (e.g., maintaining physical functions so that one can walk across a room).

- *Supportive:* Maximising functions so that patients can meaningfully participate in activities of daily living despite illness-related decline (e.g., use of Zimmer frames to transport when walking without aids becomes difficult).

- *Palliative:* Helping patients to adapt and come to terms with irreversible losses and deterioration (e.g., use of wheelchairs so that those who are unable to walk can still get around). (Definitions based on report by Hospice UK, 2015)

One aspect of palliative rehabilitation is physical therapy. This entails interventions that aim to use physical interventions (e.g., the use of adaptive and assistive equipment, modifying features of the environment, and exercise) to address patients' multifaceted health care needs (Javier & Montagnini, 2011). It is to the use of exercise and physical activity in improving the QOL of patients with advanced and chronic illnesses that I now turn.

2.5. Physical Activity, QOL, and Advanced, Incurable Disease

The use of non-pharmacological therapies (e.g., acupuncture, biofeedback, massage, and reiki) to improve QOL are becoming increasingly common within a palliative care setting (Coelho, Parola, Cardoso, Bravo, & Apóstolo, 2017). Specifically, one non-pharmacological method of improving QOL that is growing in popularity within this setting is physical activity. Reasons behind its increased use may be that it is able to limit the burden of disease through improving health outcomes (e.g., QOL, functional capacities, and length of life) without the debilitating side-effects that are often experienced when taking conventional medication (Durstine, Gordon, Wang, & Luo, 2013; Eyigor & Akdeniz, 2014).

Although the benefits of physical activity as a form of therapy for individuals with advanced, incurable diseases are now generally accepted (Albrecht & Taylor, 2012), during the 1980's it was met with scepticism, with many doctors advocating rest as a more appropriate alternative (Blaney et al., 2010; Buss et al., 2010; Jones & Alfano, 2013). There has, however, been very little evidence to support this perspective (Buss et al., 2010). In fact, whilst physical activity programmes may be difficult to implement in this population, they are certainly feasible, with recent research showing that, on the most part, individuals in palliative care recognise the value of, are enthusiastic about, and are able to tolerate physical activity (Lowe, Watanabe, & Courneya, 2009a; Oechsle et al., 2011; Oldervoll et al., 2005, 2006; Turner, Tookman, Bristowe, & Maddocks, 2016). For example, in a prospective intervention study conducted on 34 patients with advanced cancer, 63% of the sample were willing to engage in, and 54% were able to complete, a 6-week exercise program (Oldervoll et al., 2006). In patients who have been able to engage in physical activity interventions, there has been promising evidence that supports its

ability to map onto and improve the various domains of QOL that are important to those with advanced and chronic diseases.

2.5.1. Impact on physical well-being.

There has been a wealth of evidence demonstrating the role that physical activity may play in improving QOL through mapping onto the various physical needs (e.g., alleviating pain, fatigue, insomnia, dyspnoea, whilst improving physical functioning, strength, and mobility) in those with advanced cancer (Adamsen, Stage, Laursen, Rørth, & Quist, 2012; Albrecht & Taylor, 2012; Gulde, Oldervoll, & Martin, 2011; Oldervoll et al., 2005, Oldervoll et al., 2006), neurological disorders (Dalgas et al., 2010; Goodwin, Richards, Taylor, Taylor, & Campbell, 2008; Kjølhede, Vissing, & Dalgas, 2012; Pedersen & Saltin, 2015), and COPD (McCarthy et al., 2015; Spruit et al., 2016). For example, in a systematic review of 16 studies, Albrecht and Taylor (2012) demonstrated the role that various modes of physical activity (e.g., yoga, swimming, walking, biking etc.) played in improving physical functioning and alleviating symptoms such as pain, fatigue, insomnia, shortness of breath and constipation in advanced cancer patients. Furthermore, Pedersen and Saltin (2015) found that physical training interventions were able to improve gait function, muscle strength, fatigue, balance, mobility, and ability to engage in activities of daily living in individuals with Parkinson's disease and Multiple Sclerosis.

What's more, even in studies where physical activity has not been found to *significantly* improve QOL in patients with advanced, incurable disease, when compared to control groups who do not engage in physical activity, interventions can help to maintain physical functions through slowing the rate of decline (Buss et al., 2010; Headley, Ownby, & John, 2004). For example, in a randomised control trial where 16 women undergoing chemotherapy for advanced breast cancer took part in a seated exercise intervention, it was found that although QOL and fatigue scores declined in both the intervention and control groups, the rate of decline was slower in the group which engaged in exercise (Headley et al., 2004). For a population whose disease and QOL can quickly worsen, it is important to recognise that buffering the negative implications of rapid physical deterioration is an equally important - and probably a more feasible and realistic – goal of physical activity.

2.5.2. Impact on psychological well-being.

Physical activity has also consistently been demonstrated to have a facilitative impact on psychological well-being through reducing stress, anxiety, and depression, alongside improving mood and emotional functioning in those with advanced, incurable cancer (Albrecht & Taylor, 2012; Oldervoll et al., 2005; Paltiel, Solvoll, Loge, Kaasa, & Oldervoll, 2009) neurological disorders (Dalgas et al., 2010; Ensari, Motl, & Pilutti, 2014; Motl, McAuley, Snook, & Gliottoni, 2009), COPD (McCarthy et al., 2015; Spruit et al., 2016), and cardio-vascular diseases (Blumenthal et al., 2012). For example, a pilot study assessing the effect of a 6-week circuit training program on 34 advanced cancer patients found a statistically significant improvement ($p=0.002$) in patients' emotional functioning (Oldervoll et al., 2005).

Various explanations as to how physical activity can manifest into positive psychological outcomes in this population have been proposed. One explanation is the way in which it can promote a sense of positivity and relief in the face of an extremely difficult period in people's lives. For example, in a phenomenological study exploring 9 advanced cancer patients' experiences of a hospice-based gym program, Turner et al. (2016) demonstrated how engagement in physical activity helped to create a sense of achievement, thus fostered a positive outlook on their lives and selves at a time when they often felt depressed, frustrated, angry, and powerless. Another explanation that has been offered is the role that exercise can play in distracting patients from their illnesses (Gulde et al., 2011; Malcolm et al., 2016). For example, in patients with a range of advanced diseases (e.g., cancer, renal failure, Motor Neurone Disease, and respiratory conditions) a group-based seated Pilates exercise and circuit training program was able to provide a welcome distraction from their illness and an opportunity to calmly reflect on themselves and the future (Malcolm et al., 2016).

2.5.3. Impact on social well-being.

The benefits of exercise and physical activity in those with advanced disease are not constrained to improving physical and psychological well-being; they have also been found to improve social well-being (e.g., Adamsen et al., 2012; Gulde et al., 2011; Hogg, Grant, Garrod, & Fiddler, 2012; Malcolm et al., 2016; Motl et al., 2009; Paltiel et al., 2009; Turner et al., 2016). Various qualitative studies have

provided insight into the ways in which exercise may enhance social well-being in palliative patients.

For example, in a qualitative study consisting of 34 palliative cancer patients, Paltiel et al. (2009) found that taking part in group exercise program created a setting in which participants felt a sense of belonging and being cared for. For these patients, the exercise group was a place in which they could talk and share ideas about their illness and treatments with people who were in the same boat, something which was seen as a valuable aspect in helping them to cope with their illness through changing their focus from sickness to health. Similar findings on the role that group settings can play at improving social well-being through creating supportive environments in which patients feel as though they can relate to others and offload their illness experiences have been found in other qualitative studies on advanced cancer (e.g., Adamsen et al., 2012; Gulde et al., 2011; Malcolm et al., 2016; Turner et al., 2016) and COPD patients (e.g., Hogg et al., 2012).

Using exercise groups to foster a sense of belongingness and camaraderie with others in a similar predicament is also a way for patients with advanced, incurable disease to feel less isolated (Adamsen et al., 2012; Hogg et al., 2012; Malcolm et al., 2016). For example, in patients with COPD, being able to interact with other people who were part of their exercise group acted as a way to reduce feelings of isolation that often accompanied living with chronic disease (Hogg et al., 2012). In addition to the role that social interaction plays in improving social well-being, physical activity has also been found to help patients get outside of their home environment and provide a meaningful activity that can provide structure, routine, and purpose to their lives (Gulde et al., 2011; Malcolm et al., 2016; Paltiel et al., 2009).

2.5.4. Impact on existential well-being.

Physical activity has also been found as a means through which palliative patients can improve perceptions of their existential well-being. For example, in a study exploring the associations between physical activity and QOL in 50 advanced cancer patients, Lowe, Watanabe, Baracos, and Courneya (2009b) found a moderate to strong association between higher physical activity levels and existential well-being. They proposed that physical activity (e.g., walking more than 30 minutes

per day) was something that could provide and maintain meaning in participants' lives through delaying disease-related functional impairments and decline.

Indeed, other research within the literature has supplemented this assertion (e.g., Burke et al., 2013; Gulde et al., 2011; Malcolm et al., 2016; Turner et al., 2016). For example, in their phenomenological study exploring 10 advanced rectal cancer patients' perceptions of QOL after engaging in a 6-week pre-operative aerobic exercise program, Burke et al. (2013) demonstrated how participation could improve existential well-being. For these participants, diagnosis of advanced cancer meant that they had to undergo various lifestyle changes (e.g., stopping work) which left many feeling as though their life lacked meaning and purpose. Physical activity, however, offered them an avenue through which they could feel proactive in dealing with their disease, thus fostered a sense of purpose and direction in their life. As well as improving existential well-being through assisting patients in finding meaning in their lives, Gulde et al. (2011) highlights how physical activity is also a way for patients with advanced, progressive diseases to foster hope for the future. This was because they saw it as a potential means through which they could preserve physical functions, prolong their lives, obstruct the spread of disease, and improve their overall QOL.

Within the literature concerned with physical activity and QOL in patients with terminal and chronic illnesses, the majority of studies utilise interventions that are based solely on physically moving the body (e.g., gym-based training programmes, physical training, walking, swimming, biking etc.). Consequently, the utility of forms of physical activity which centre their philosophies on the unification of the mind and body, have generally been overlooked in this field.

2.6. Mindful Movement

For many of the same reasons as physical activity (i.e., its ability to relieve suffering without adverse side-effects associated with conventional medication) the use of mindfulness-based therapies are becoming increasingly popular as non-pharmacological adjuncts to improving QOL in a palliative care context (Elkins et al., 2010; Latorraca, Martimbianco, Pachito, Pacheco, & Riera, 2017). The concept of mindfulness is rooted within Buddhist traditions and is often associated with the

practice of meditation (Shapiro, Carlson, Astin, & Freedman, 2006). Brown and Ryan (2003, p.822) liken it to a state of consciousness in which an individual is "attentive to and aware of what is taking place in the present". This may be achieved through two separate (but related) mindfulness techniques: concentration (samatha) and insight (vipassana) (Kabat-Zinn, 1982; Grabovac et al., 2011; White, 2014). The samatha approach is an attention regulation practice which entails concentrating one's attentional focus entirely on a specific object/ point of focus whilst suspending thought of all other things. For example, paying close attention to one's breathing pattern whilst actively ignoring and re-directing attention away from any other information that may enter the mind. The vipassana approach, on the other hand, refers to an insight-oriented practice which presupposes concentration. Rather than restricting one's attention to a singular object or point of focus, the vipassana approach to mindfulness emphasises a moment-to-moment, detached observation (e.g., observing objects without prescribing them value or interpreting them) of a continuously changing field of objects, and include all mental and sensory events that are occurring in situ (Baer, 2003; Kabat-Zinn, 1982). Fundamental to both mindfulness techniques is the focus on the *quality* of experiences that are occurring in the present moment.

The use of mindfulness-based movement therapies (MBMT) (e.g., Tai Chi, Qigong, Yoga, Pilates etc.) are gaining traction within this community. MBMT's integrate the mind, body, and spirit and have been defined as physical exercises which are completed with an explicit and profound contemplative (e.g., inward and non-judgemental) focus on the embodied, kinaesthetic, and proprioceptive qualities of movement (La Forge, 2005). Whilst MBMT's incorporate exercise, the focus of these interventions is not on exercise per se; they involve much more than simply moving the body (Lucas, Klepin, Porges, & Rejeski, 2018). Lucas et al. (2018) propose three structural components which highlight the uniqueness of MBMT interventions.

The first is that they encompass a multitude of activities and intensities, ranging from postural shifts and activities of daily living to moderate and vigorous exercise. In this way, MBMT's are appreciative of the effects that small and simple movements can exert on our physical and emotional QOL. The second characteristic of MBMT's is that they encourage active living through promoting movement as a

mode of "being" as opposed to "doing". That is, rather than seeing mindful movement as something which must be "done", almost in a chore-like fashion, they are activities that seek to (re)instil an appreciation of the inherent joy of movement through anchoring a person's awareness to present mind and body states. Thirdly, MBMT's are group-based activities which pertain relational value through the creation of safe and supportive environments in which participants can connect with others and experience a common sense of humanity through the process of mindful movement.

These three characteristics demonstrate how MBMT's are based on the notion that the mind is at once embodied (e.g., it is intimately connected with, and receives information and energy from, the body) and relational (e.g., it enables us to develop important connections and relationships with others and the environment) (Lucas et al., 2018). Thus, they represent a contrast from conventional exercises and physical activities which – through pertaining a predominant focus on the physical movement of bodies - treat the mind and body in relatively disconnected ways (La Forge, 2005).

2.7. Qigong and Tai Chi

Qigong is an umbrella term which encapsulates a multitude of mindfulness-based exercise styles which integrate breathing, body, and mind adjustment into one (Klein, 2017; La Forge, 2005). It is based on ancient Chinese notions of "Qi" which represents "vital energy", or "life force" (Klein, 2017). This "vital energy" is said to be central to our health and well-being in that elevated levels are able to invigorate us, protect from disease, enhance our clarity of thought, and improve the ability to learn (Klein, 2017; Wayne & Fuerst, 2013). The opposite also holds true in that reductions or blockages of Qi disrupt and undermine an individual's health and QOL. Thus, in order to prevent these blockages, the practice of gentle mind-body exercises is used to optimise its balance and flow through meridians (or pathways) in the body (Klein, 2017; La Forge, 2005).

One such form of Qigong is Tai Chi (sometimes referred to as t'ai chi ch'uan, taijuquan, tai ji quan, or tai ji chuan) (Wayne & Fuerst, 2013). Tai Chi derives from the practice of Chinese martial arts and has been utilised within a healthcare context to improve health, well-being, and QOL (La Forge, 2005). La Forge (2005) notes many different styles of Tai Chi exist (e.g., original Chen form, Yang, Chang, Wu,

and Sun), each of which place particular emphasis on certain aspects of practice. For example, some styles place a heightened focus on breathing and relaxation whist others emphasise the generation of power. Whilst each style differs slightly in approach, they are all grounded in the same philosophy which proposes that through the combination of lucid bodily movements, breathing, and self-awareness/mindfulness, the flow of Qi throughout the body can be facilitated (La Forge, 2005). Thus, Wayne and Fuerst (2013, p.1) define it as:

> a mind-body exercise rooted in multiple Asian traditions, including martial arts, traditional Chinese medicine, and philosophy. Tai Chi training integrates slow, intentional movements with breathing and cognitive skills (for example, mindfulness and imagery). It aims to strengthen, relax, and integrate the physical body and mind, enhance the natural flow of Qi, and improve health, personal development, and self-defense.

Whilst the above definition focuses primarily on the integration of the mind and body, Tai Chi is also relational in that it seeks to cultivate a strong sense of community through tuning individuals in with other people and objects that are located within their social and natural environments (Wayne & Fuerst, 2013). Based on this definition and their extensive research and practice of Tai Chi, Wayne and Fuerst (2013) propose that Tai Chi consists of eight active and synergistic ingredients including: awareness; intention; structural integration; active relaxation; strengthening and flexibility; natural freer breathing; social support; and embodied spirituality. Across the different Tai Chi styles, these ingredients amalgamate to form the core overarching constructs which underpin Tai Chi practice.

2.7.1. Core overarching constructs.

When taken together, Tai Chi consists of four main overarching constructs: (a) the embodied mind; (b) attention and awareness; (c) intention and attitude; and; (d) self-compassion. A brief introduction to each of these concepts are given in the following paragraphs.

The embodied mind. Western medical practice has long adopted a dualistic and reductionist approach to health and well-being, treating the body and mind as metaphysically separate entities (Mehta, 2011; Stewart, 2015). Following Cartesian logic, in the same way that mechanics do a car, this mode of medicine views the

body as a machine in which disease is seen as a breakdown of normal function which needs to be physically repaired (Mehta, 2011; Stewart, 2015). Likewise, the mind is detached from the body in that individuals are construed as "rational actors" whose cognitive processes are located exclusively in a mind which is detached from, and in no way affected by, the body (Howson & Inglis, 2001; Reeve et al., 2010). Thus, historically, in the treatment of dysfunctions of the mind and body, healthcare has adopted a sequestered approach in which the field of medicine exclusively deals with physical issues, whilst the field of psychiatry and psychology addresses issues to do with mental and cognitive processes (Stewart, 2015; Wade, 2006).

Whilst the innovations and successes of reductionist approaches should be celebrated, in fragmenting and dividing problems into single parts, important information about the whole is lost (Wayne & Fuerst, 2013). Because Tai Chi is lodged within Eastern holistic and ecological views of health (e.g., treating people as "wholes", at once consisting of the physical, psychological, social, and spiritual) it represents a break from, and challenge to, Western, Cartesian conceptions of health and medicine. Rather than fragmenting the mind and body, fundamental to the practice of Tai Chi is the integration of the two through merging rhythmic movements, breathing, and physical postures with cognitive and emotional components such as visualisation, imagery, focused attention, and self-awareness (Osypiuk, Thompson, & Wayne, 2018; Wayne & Fuerst, 2013). Thus, the relationship between the mind and body during Tai Chi is reciprocal in that changes in our physiology and body postures can inform and affect our mental states and vice versa. In this way, Tai Chi adopts the notion of the "embodied mind", that is: "there is mind in the body and body in the mind… we are always both mind and body" (Bullington, 2013, p.25). It is through the embodied mind that individuals are able to focus their attention and awareness on physical and mental states that are occurring in the present.

Attention and awareness. According to Brown and Ryan (2003) the human consciousness encompasses awareness and attention. Whilst *awareness* is broad and represents a kind of "radar" which continuously picks up stimuli that are present within the internal or external environment, *attention* is a process of focusing one's awareness on a narrow aspect of experience (Brown & Ryan, 2003). In the context of Tai Chi, the notion of attention refers to an active process through which an

individual consciously directs their focus on aspects of present, moment-to-moment experiences in order to enhance the levels and flow of Qi throughout the body (Shapiro et al., 2006). Attentional focus may be directed towards the body (e.g., the qualities of relaxing and gentle movements), mind (e.g., imagery and visualisation), breathing (e.g., fostering free, more natural breathing patterns), or social environment (a sense of community with others) (Wayne & Fuerst, 2013). For example, intently focusing one's attention on the process of free and natural breathing (e.g., how air effortlessly enters through the nostril, soothes the windpipe and expands the chest) is said to draw in vital energy (Qi) from the external environment and distribute it throughout the body (Wayne & Fuerst, 2013). In cases where the mind wanders and strays, thus disrupts our focus, it is purposefully re-directed back to the subject of the present moment (Klein, 2017; Wayne & Fuerst, 2013).

Through the process of directing and re-directing one's attention on what is occurring in the here and now, Tai Chi actively cultivates an intense and acute *awareness* of internal mental and sensory experiences that are occurring within the mind and body in the present moment (Wayne & Fuerst, 2013). Implicit within these states of awareness is a focus on "being" as opposed to "doing". That is, rather than allowing the mind to be preoccupied by the stresses, fast-moving, and problem-solving orientation of everyday life, through fostering a deep, inner awareness of our minds and body, Tai Chi allows us to shift our attention and awareness onto simply "being" (i.e., simply enjoying moment-to-moment experiences) (Dimidjian, Kleiber, & Segal, 2010; Wayne & Fuerst, 2013). Adopting specific intentions and attitudes are integral to reaching these states of mindfulness during Tai Chi sessions.

Intention and attitude. Intention is the reason as to why Tai Chi is being practiced (Shapiro et al., 2006) and represents the beliefs and expectations that we hold before entering Tai Chi sessions (Wayne & Fuerst, 2013). In Tai Chi, intention refers to "meditative intent" (or "Yi"), and translates as: "where the mind goes, the energy flows" (Klein, 2017, p.4). The idea being that through conscious attempts to reach a mindful state (e.g., through the use of imagery/visualisation or metaphors from nature) we can better focus our attention and reach states of awareness and meta-awareness, thus complement the therapeutic effects associated with Tai Chi (Wayne & Fuerst, 2013). This is because Yi connects our minds with our bodies

through cultivating the accumulation, circulation, and storage of vital energy through pathways in our bodies (Klein, 2017).

Embedded within our intentions and attention is *attitude.* Attitudes are the evaluations that we prescribe to our experiences (White, 2014). Central to Tai Chi is the adoption of an accepting, non-judgemental, and open attitude in which one is able to observe sensory and mental experiences in the present without habitually reacting to or making cognitive judgements of them. For example, if a cloud movement during Tai Chi exacerbates a twinge in the muscle, rather than evaluating the experience and lacing it with meaning (e.g., '"ouch that hurts"), an individual simply observes its transitory nature and accepts it as a "mere thought" that is part of their moment-to-moment experience. Through becoming an observer, as opposed to a subject of experiences, a state of meta-awareness, thus mindfulness, can be achieved. A specific type of attitude that is important in reaching states of mindfulness during Tai Chi is self-compassion.

Self-compassion. The concept of self-compassion is an important notion within Buddhist philosophy (Neff, 2003). Describing what is meant by self-compassion, Neff (2003, p.86-87) defines it as:

> being touched by and open to one's own suffering, not avoiding or disconnecting from it, generating the desire to alleviate one's suffering and to heal oneself with kindness. Self-compassion also involves offering non-judgmental understanding to one's pain, inadequacies and failures, so that one's experience is seen as part of the larger human experience.

Based on this definition, self-compassion consists of three constructs: (a) self-kindness (e.g., an understanding and kindness, as opposed to a critical and harsh approach to oneself); (b) common humanity (e.g., an appreciation that one's own experiences and sufferings are part of a shared human experience); and (c) mindfulness (e.g., not over-identifying with thoughts and feelings) (Neff, 2003).

Taken together, these "three faces" of self-compassion comprise a specific type of attitude towards oneself (White, 2014). The kind and non-judgemental nature of self-compassionate attitudes provides an "emotional safety net" through which one can view internal mental and physical events in the present more transparently, without becoming overwhelmed by them or engaging in self-criticism (Neff, 2003). In

this way, self-compassion is an important mediator in fostering the types of focused attention and mindfulness that are fundamental during Tai Chi practice.

Furthermore, through their appreciation of a shared humanity with others, self-compassionate attitudes are in line with the social aspects of Tai Chi. That is, central to Tai Chi practice is the sensitisation and integration of the self with other people through tuning into one's social environment (Wayne & Fuerst, 2013). Because self-compassion is characterised by allowing oneself to be open to and touched by the suffering of others, it allows individuals to form connections and relieve distress through appreciating the commonality of human experience (Neff, 2003).

2.7.2. Tai Chi and Quality of Life in Advanced, Incurable Disease.

The use of mind-body therapies such as Tai Chi are becoming increasingly popular within Western healthcare practice (Lan, Lai, & Chen, 2002; Wayne & Fuerst, 2013). Specifically within palliative care contexts, one reason behind the increased use of Tai Chi may be because it's underlying philosophy (i.e., a holistic, person-centred, and ecological approach to health, well-being, and medicine) is directly compatible with the ethos on which hospice and palliative care is built. Another reason could be that Tai Chi practice can be easily modified in ways that make it feasible and accessible to the heterogeneous abilities and disease types (which often differ in severity) that are present within the palliative population (Li, Yuan, & Zhang, 2014; Zheng, Luo, Xie, Huang, & Cheng, 2014). Because of its safe and feasible nature which is commensurable with palliative care's holistic approach to care, Tai Chi has the potential to map onto the physical and psychosocial needs that are important to individuals with chronic and advanced, incurable diseases (Zheng et al., 2014).

There has been evidence to support the role that Tai Chi can play at improving various domains of QOL in the disease types that make up the palliative population. Recent systematic reviews and randomised trials including patients with neurological disorders (e.g., Cwiekala-Lewis, Gallek, & Taylor-Pilia, 2017; Li et al., 2012; Song et al., 2017), advanced cancers (e.g., Chuang, Yeh, & Chung, 2017; Oh et al., 2010; Oh et al., 2012; Vanderbyl et al., 2017; Zhang, Wang, Chen, & Yuan, 2016), cardio-vascular diseases (such as heart failure and coronary heart disease) (e.g., Dalusung-Angosta, 2011; Ng et al., 2012; Wang et al., 2016), and COPD (e.g.,

Guo et al., 2016; Lueng, McKeough, Peters, & Alison, 2013; Polkey et al., 2018) have demonstrated the positive role that Tai Chi and similar interventions such as Qigong can have on physical functions/symptoms, psychosocial well-being, and overall QOL.

In a review of 21 studies (15 of which were RCT's) Song et al. (2017) demonstrated that in patients with Parkinson's disease, Tai Chi was associated with significant improvements in baseline scores across various motor outcomes such as balance, mobility, and gait as well as reducing levels of depression. Other studies have demonstrated how Tai Chi is more effective at improving health outcomes in this population than conventional exercise. For example, in a randomised control trial (Zhang et al., 2016) 96 lung cancer patients (of which 59 were in advanced stages of their disease) were evenly split into 12 weekly 1-hour Tai Chi sessions or low-impact exercise groups. The results showed that Tai Chi sessions were able to significantly lower cancer-related fatigue and improve vigor when compared to the exercise control group. Similarly, another randomised control trial on patients with COPD showed that when compared to control groups and a walking/breathing intervention, Tai Chi was able to significantly improve lung functions (e.g., FEV1 and vital capacity) and exercise capacity (e.g., walking distance) (Chan, Lee, Suen, & Tam, 2011).

To date, only two studies have explored the impact of Tai Chi on patients' experiences of progressive, advanced disease utilising qualitative methods (Hägglund, Boman, & Brännström, 2018; Yeh, Chan, Wayne, Conboy, 2016). These have demonstrated that Tai Chi could improve perceptions of physical abilities (e.g., improvements in pain, balance, breathing, energy, and activities of daily living), help to manage stress, enhance feelings of control, and provide an opportunity to exercise with other people who had a shared understanding of illness. For example, in a mixed-methods study, Hagglund et al. (2018) utilised semi-structured interviews to explore how taking part in twice weekly 60-minute Tai Chi sessions over a period of 16 weeks impacted patients' perceptions of chronic heart failure. The results showed that Tai Chi was perceived as a feasible and meaningful activity which participants could use to meet other people suffering from similar problems to them. It was also an opportunity for them to improve their perceptions of health (e.g., improving breathing, balance, and fitness) whilst fostering states of calmness.

Similarly, in a qualitative sub-study of a larger randomised control trial, Yeh et al. (2016) utilised semi-structured interviews to investigate the differences between a 12-week Tai Chi program and education control group on HRQOL in 32 patients with chronic heart failure. For participants in the intervention group, Tai Chi was an empowering experience which allowed them to appreciate the intimate connection between, and feel confident in taking control and ownership over, their minds and bodies. Furthermore, through fostering a heightened awareness of their bodies and social environments, Tai Chi was able to help participants manage stress and connect with those around them.

2.8. PhD Project: Rationale, Aims, and Research Questions

Because living with advanced, incurable disease can undermine the QOL of patients and their families, evidence-based interventions that can enable patients to live well until they die are needed. This type of research is especially timely considering the increased need for palliative care that is to be expected in the coming decades. Indeed, Hospice UK (2015, p.6) recognise that "there is now a need for a relentless focus on improving outcomes, including people's experience and quality of care, wherever the setting." If, in responding to the challenge of increased need, palliative care is to retain its unique philosophy which makes it so apt at addressing the needs of terminally ill patients, it is crucial that interventions resist the "routinization and medicalization of palliative care" (Floriani & Schramm, 2012, p. 301). This includes an overemphasis on interventions which foreground addressing patients' physical – often at the expense of their psychosocial and existential – needs. Because Tai Chi is a holistic activity (e.g., it incorporates the mind, body, spirit, and social environment) – and one that is relatively easy to deliver in a palliative care context - it presents a unique form of movement that has the potential to achieve this.

Despite the holism that underpins Tai Chi practice, research that has explored its impact on QOL in terminally ill patients has been dualistic, disembodied, and decontextualized. That is, most studies have fragmented and compartmentalised the various domains of QOL through using quantitative outcome measures that focus exclusively on specific physical and psychological variables (e.g., Time-Up-and-Go tests, Functional Reach Tests, 6 minute walking test, Short Form-36, Chronic

Respiratory Questionnaire, St George's Respiratory Questionnaire etc.). Therefore, whilst initial findings have provided support on the QOL benefits of Tai Chi in patients with advanced, incurable disease, there is still a gap in our understanding surrounding the mechanisms of *how* it does (Li et al., 2014; Yeh et al., 2004). Furthermore, there is also no research that has explored how terminally ill patients' experiences of Tai Chi are located within the specific socio-cultural environment of hospice day care. This is important considering that hospices present one of the few places in the community in which patients with advanced disease have the opportunity and provision to engage in mindful movement therapies like Tai Chi.

The aims of this study, therefore, were to utilise an ethnography to: (a) explore how patients' experiences of participating in hospice-based Tai Chi shaped their perceptions of QOL using Calman's (1984) gap theory (see chapter 3.2) as the guiding conceptual framework; and (b) explore patients' views on hospice-based Tai Chi, including identifying perceived barriers and facilitators to participation using McLeroy, Bibeau, Steckler, & Glanz's (1988) social ecological approach (see chapter 3.3). In doing so, this is the first study of its kind to utilise the ethnographic method to form a contextualised and patient-centred understanding of how taking part in a hospice-based Tai Chi program impacts perceptions of QOL in patients with terminal illness.

In accordance with these aims, therefore, this project was guided by the following research questions:

1. How does participation in hospice-based Tai Chi impact on patients' perceptions of their QOL?

2. What are patients' views on, and the barriers and facilitators that they face in relation to, participating in Tai Chi within the socio-cultural context of a hospice day therapy unit?

2.9. Summary

In this chapter I have given an overview and discussion of the relevant literature, theories, and concepts that are related to this PhD project. This has included exploring constructs including QOL, HRQOL, well-being, and mindfulness,

and showing how these intersect with the fields of physical activity/mindful movement and palliative care. This (in part) provides the reader with the relevant background needed to locate and understand the content of this thesis, particularly the empirical findings that are presented between chapters 6-9. This research project is the first ethnography to explore how terminally ill patients experience and view Tai Chi within the context of hospice day care. In doing so, it endeavours to expand our understanding of the ways in which hospice-based mindful movement therapies (specifically Tai Chi) may impact perceptions of QOL in patients with advanced, incurable disease. It also aims to enhance our understanding of the ways through which we can make these programs more accessible for patients in this population by exploring factors that may enable and preclude participation. The next chapter provides an overview of the conceptual frameworks that guided the aims and research questions of this study.

Chapter 3: Conceptual Frameworks

3.0. Overview

Conceptual frameworks are models which either describe, explain, or predict the relationships between elements of a concept (Taillefer, Dupuis, Roberge, & LeMay, 2003). They assist in moving understanding beyond mere observations through organising knowledge into frameworks in which statements made about these relationships can be tested and explored in further detail (Roop et al., 2012). Within ethnographic inquiry, researchers should enter the field with a conceptual framework through which to explore their research question within specific cultural settings (Creswell, 2013; Fetterman, 2010; Wolcott, 2005). The two conceptual frameworks that were used as part of this project were the Gap Theory of QOL (Calman, 1984) and the Social Ecological Model (SEM) of physical activity behaviour (McLeroy et al., 1988)

3.1. Calman's Gap Theory to Quality of Life

Calman's gap model is built on the fundamental premise that QOL represents the discrepancy between an individual's reality (i.e. what is occurring in their life in the present moment) and their hopes, dreams, and ambitions (i.e. where they want to be). In this way, QOL would be deemed to be good if an individual's hopes and dreams are fulfilled by their current life experience and poor when there is a large divergence between the two. For example, if an individual with advanced cancer held the value that feeling socially and emotionally connected was important to their QOL, and they felt they were surrounded by supportive networks of people who cared for and understood what they were going through, a good QOL could be said to be had. If, however, they felt they were alienated, stigmatised, and sequestered from others, the opposite (i.e., a poor QOL) would be expected.

Premising QOL in such a way leads to various implications that are integral to Calman's gap theory. These are that QOL is:

1. *Subjective:* it can only be described and understood from the viewpoint of participants and is contingent on *their interpretations of* current life

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situations, past experiences, and hopes, dreams, and ambitions.

2. *Multi-dimensional:* it assumes the importance of including multiple areas of life and experience when attempting to understand how illness and treatment can impact QOL.

3. *Amenable to growth*: severe illnesses are still a point in individuals' lives where growth can be experienced. This is because QOL consists of various domains, so even when one aspect of an individual's QOL is unfulfilled (e.g., physical wellbeing) they are still able to grow in other ways (e.g., socially).

4. *Dynamic:* because interpretations of life events can vary across different times and contexts, QOL is dynamic and represents what Calman (1984, p.125) calls a "constantly changing picture."

5. *Holistic:* through recognising patients as "whole persons", notions of QOL extend beyond the impact of symptoms and treatments through appreciating that individuals are comprised of mind, body, and spirit. Through doing so, it is compatible with the ethos which underpins palliative care and mind-body therapies such as Tai Chi*.

6. *Improved through direct action:* in a palliative care context, improving QOL is achieved via the utilisation of task-orientated interventions that reduce the discrepancy between patients' present reality and their hopes and expectations. This may either be through improving their moment-to-moment experiences or reducing their expectations. Expanding on the example given of the cancer patient above, QOL could be improved by either fostering environments which are conducive to feeling cared for and understood or changing the patient's values on what they should come to expect in regards to others' reactions to their illness.

These premises were the basis through which I sought to explore how taking part in Tai Chi impacted participants' experiences of QOL in this study.

3.2. Social Ecological Model of Physical Activity

Neoliberalism is an ideology that "places the individual at the nexus of concentric circles of influences" (Tulle, 2017, p. 171). Whilst it is fair to assume that individuals do hold some agency in regard to health behaviours, this ideology strips human experiences and the reasons as to why we may be physically active (or inactive) from larger socio-cultural and environmental influences (Kelly & Barker, 2016; Tulle, 2017). This has culminated in what McLeroy et al. (1988, p.351) called a "victim-blaming ideology", in which being physically inactive is seen entirely as a personal choice, thus represents a personal failure of the individual. Interventions informed by such an ideology, therefore, have placed too much emphasis on changing individuals and their behaviours without seeking to modify aspects of the socio-cultural and political environments in which they are embedded (McLeroy et al., 1988).

Social Ecological Models (SEM) of health and physical activity promotion offer an alternative to this ideology through offering a conceptual framework that recognises the relationship between, thus integrates, individual factors and the environmental, social, and political contexts in which they reside (McLeroy et al., 1988; Sallis, Owen, & Fisher, 2008). In SEM's, it is proposed that a reciprocal relationship between the personal and social exists in that "appropriate changes in the social environment will produce changes in individuals, and that the support of individuals in the population is essential for implementing environmental changes." (McLeroy et al., 1988, p.351). In representing this relationship, therefore, factors which influence health behaviours such as a physical activity exist on multiple interacting and dynamic levels, including: intrapersonal, interpersonal, organisational/environmental, community, and policy (see figure 2) (Boulton, Horne, & Todd, 2018; McLeroy et al., 1988).
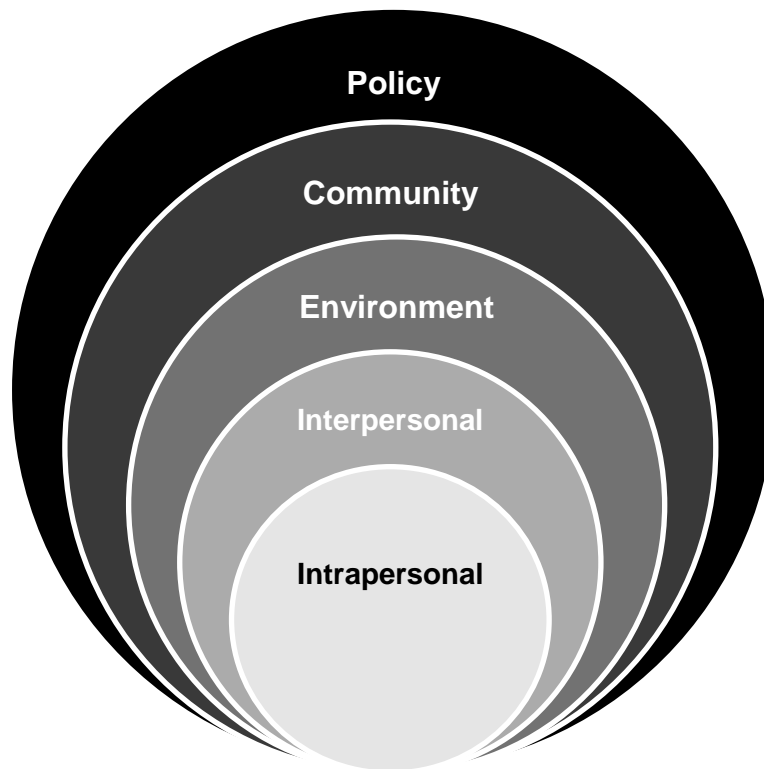
Figure 2: *A social-ecological model of physical activity adherence and maintenance (McLeroy et al., 1988).*

Intrapersonal factors represent features of the individual that may influence the adoption and maintenance of physical activity such as demographics, motivations, beliefs, attitudes, identity, skills etc. (McLeroy et al., 1988; Sallis et al., 2008). The mechanisms for behaviour change interventions at this level, therefore, have been based on psychological models (e.g., social learning theory, operant conditioning, attribution theory etc.) which focus on changing the individual rather than aspects of their social environments (McLeroy et al., 1988). *Interpersonal factors* are the norms that exist within social networks, and relationships with friends, family members, and colleagues that influence the promotion of physical activity. *Organisational/environmental factors* are the extent to which specific institutions in which individuals reside support, act as targets for, and offer opportunities to be, physically active. *Community factors* relate to the meso-systems which act as mediating structures to health promotion, relationships between various organisations (e.g., NHS, hospices, local councils, government health department), and the political systems and power structures in which people live. *Public policy*

factors are the way that governmental and local council policies, laws, and procedures are used to promote physical activity.

Based on these levels, Sallis et al. (2008) proposes 4 principles on which SEM interventions are built: (a) there exists multiple levels that influence physical activity behaviour; (b) factors across multiple levels interact to influence physical activity (e.g., interpersonal factors such as a supportive and safe friendship group may interact with intrapersonal levels of motivation to remain physically active); (c) multi-level interventions (as opposed to interventions that focus on factors residing in single-levels) are the most effective for changing behaviour; and (d) SEM's are most powerful when they focus on specific behaviours. The ultimate aim of SEM interventions is to use these principles through targeting various levels of influence in ways that create environments and policies that are conducive to behaviour changes and then motivating and educating individuals into making positive health choices (Sallis et al., 2008). Fundamental to this process is actively engaging the target population in the design, implementation, and evaluation of physical activity interventions through a process of consensus building (McLeroy et al., 1988). Through using the SEM as a guiding conceptual framework, this is what the second aim of this project seeks to achieve.

3.3. Summary

This chapter has given an overview of the conceptual frameworks that guide this study. This further supplements chapter 2 by providing the reader with an understanding of the conceptual lenses that I used in order to make sense of the data in this project. Of course, these provided only one perspective through which my research questions may have been understood. However, after carefully examining the various potential conceptual frameworks that I could have used to guide this project, I concluded that these were the two most appropriate. Now that I have provided all of the relevant background that pertains to this PhD project, the next chapter provides an in-depth description of the methods and methodology through which this study was conducted.

4.0. Overview

In this chapter I describe the methodology and methods that I adopted in answering my research questions. I start by offering an outline of the epistemological and ontological assumptions that underpin this project and then proceed to describe the methodological approach (i.e., an ethnography) that I used as a guide to inquiry. Following this, I describe the ways through which I collected, analysed, and represented data, alongside how I navigated various ethical issues pertinent to this project. I also provide the reader with lists of possible criteria which they may use in judging the quality of this PhD project. Laced throughout each part of this chapter are the rationales and justifications behind *why* I adopted my chosen methodology and methods.

4.1. Qualitative Method

Qualitative research is void of an unambiguous and universal definition (Sparkes & Smith, 2014). This is largely due to the heterogeneity of approaches and methods that it entails. Indeed, Madill and Gough (2008) propose that qualitative research in the 21st century is best understood as a "fuzzy set". That is, it:

> consists of clusters of methods with features in common that overlap, in some respects, with other clusters, while at the same time, some methods have no obvious features in common with other methods. To complicate matters further, because qualitative methods can be clustered in different ways, no typology is definitive. (Madill & Gough, 2008, p.255)

Accordingly, qualitative research consists of a multitude of overlapping traditions, methods, and methodologies (Sparkes & Smith, 2014). Whilst there is much difference between the ways in which academics may conceptualise and conduct qualitative research, it comprises of various defining features/characteristics that help in understanding what it entails.

The first is that is focuses on lived experiences and meaning (Sparkes & Smith, 2014). Generally speaking, therefore, it "is a form of social inquiry that focuses on the way people interpret and make sense of their experiences and the world in which they live" (Sparkes & Smith, 2014, p.14). It relies on textual or visual

(as opposed to numerical) data as a means of representing these experiences (Sparkes & Smith, 2014). Another way of understanding qualitative research is through the paradigmatic and philosophical assumptions that it commonly adopts. Most – although not all – qualitative researchers subscribe to relativist ontologies (i.e. reality is multiple) and subjectivist, transactional, and constructionist epistemologies (i.e. knowledge is socially constructed through interactions) (see chapter 4.2) (Smith & Caddick, 2012; Sparkes & Smith, 2014). From this perspective, the researcher and researched are inextricably intertwined meaning that the "findings" or "results" from any qualitative research project are co-constructed between the knower and known (Smith & Caddick, 2012). Thus, researchers must "position" themselves in their work through maintaining a continuously reflexive stance with regards to how their values and beliefs may bias and distort the research process and product (Creswell, 2013, see chapter 1.2).

There are various reasons as to why the qualitative approach was chosen to conduct this project, the first being that it was conducive to answering the research questions that underpinned my study. Adopting qualitative methods allowed me to collect a vast amount of rich, detailed, and in-depth data surrounding participants' views and experiences of Tai Chi. Furthermore, because it also dedicates itself to understanding how these experiences and meanings are situated within natural contexts it was the perfect way for me to explore how participants' experiences and views of Tai Chi were located specifically within the socio-cultural environment of hospice day care (Smith & Caddick, 2012; Sparkes & Smith, 2014). In doing so, adopting a qualitative research design allowed me to embrace the complexity, nuance, and layered nature of participants' experiences (Creswell, 2013; Smith & Caddick, 2012).

Another reason as to why qualitative research was used in this project was that it permitted me to immerse myself within the hospice context over prolonged periods of time to understand my research questions. This was essential for conducting my ethnography as it allowed me to get as close as I could to participants in the hospice environment through "being there" with them over a 6-month period (Wolcott, 2005). It was through doing so that I was able to understand participants' behaviours, values, and beliefs of Tai Chi from an insider, or "emic", perspective (Krane & Baird, 2005). Finally, qualitative research dedicates itself to comprehending

the processes through which phenomenon occur (Sparkes & Smith, 2014). Thus, it allowed me to explore the mechanisms through *how* participants experienced Tai Chi in relation to their QOL over time.

4.2. Ontology and Epistemology: An Interpretive Paradigm

The term "research paradigm" refers to a "set of basic beliefs…a worldview that defines, for its holder, the nature of the "world", the individual's place in it, and the range of possible relationships to that world and its parts" (Guba & Lincoln, 1994, p.107). These paradigms are multiple (e.g., positivism, postpositivism, interpretivism, post-modernism etc.) and each of them take on different positions regarding ontological (e.g., questions surrounding the nature of reality) and epistemological (e.g., questions surrounding the nature of knowledge) assumptions (Crotty, 1998; Krane & Baird, 2005). Assumptions surrounding ontology and epistemology are fundamental to the research process because they inform and subsequently impact the research process and product. Although not always explicit, the stances that a researcher adopts assists in defining research problems, dictates how they conduct inquiry, and influences the criteria through which they seek to legitimise the credibility of such work (Fetterman, 2010; Smith & Caddick, 2012; Sparkes & Smith, 2014). This thesis was grounded in an interpretivist paradigm which is "predicated upon the view that a strategy is required that respects the differences between people and the objects of the natural sciences and therefore requires the social scientist to grasp the subjective meaning of social action" (Bryman, 2004, p.13).

Within this interpretive paradigm, the present project was underpinned by ontological relativism and epistemological constructionism. Ontological relativism proposes that although physical things do exist independently to ourselves, our understandings of them are shaped by our minds through meaning-making processes (Sparkes & Smith, 2014). This is not to say that:

> the mind 'creates' the world of objects or what people say or do. Rather, it means that how we give meaning to objects and how we interpret the movements and utterances of other people, in terms of the motivations and meanings we assign to them, are shaped by the determining categories of the mind via, for example, language and cultural symbolism. (Sparkes & Smith, 2014, p. 11)

Accordingly, singular and objective truths do not exist. Instead, reality is socially constructed and is therefore multiple and subjective. With this in mind, epistemological constructionism proposes that the relationship between the researcher and researched is symbiotic whereby understandings of phenomenon are co-constructed through interactions between the two. In consequence:

> there can be no separation of the researcher and the researched, and values always mediate and shape what is understood. The knower and the known are interdependent and fused together in such a way that the findings are the creation of a process of interaction between the two. (Sparkes & Smith, 2014, p.13)

The fusing of ontological relativism and epistemological constructionism provides the underlying philosophical framework for this project; social constructionism. Burr (2003) outlines the four central tenets to social constructionism: (a) it challenges the notion of objective knowledge, thus is inherently opposed to positivism and essentialism; (b) our understanding of the world is historically and culturally relative; (c) knowledge is the product of social processes/interactions; and (d) how we come understand and assign meaning to the things in our world impacts how we behave in it. Thus, the findings of this project do not simply reproduce an objective and fixed reality of participants' views and experiences of Tai Chi, rather, they represent the co-construction of knowledge between myself and the research participants. Adopting such a framework allowed me to understand the subjective experiences and perceptions of participants and how these were located, shaped, and moulded within the cultural context of the hospice.

4.3. Ethnographic Inquiry

Ethnography was the design utilised to explore the research questions in this project. In challenging positivism, ethnography functions in the "new paradigm inquiry" (Lincoln & Guba, 2000) of qualitative research, meaning that it adopts an inductive and interpretive approach in which the notion of value-free and factual observations is regarded a myth (Krane & Baird, 2005). Because it is part of qualitative research's "fuzzy set" (Madill & Gough, 2008, p.253) in which it shares features and overlaps with other qualitative approaches, definitions of ethnography

are varied and contested (Hammersley & Atkinson, 2007). Indeed, over time, its meaning has been reinterpreted and remoulded to suit the research contexts and questions to which it has been applied (Hammersley & Atkinson, 2007). However, there are various characteristics unique to ethnographic inquiry which differentiates it from qualitative research per se and other methodologies that are used within this approach. Perhaps most importantly, for a piece of work to be legitimately labelled an ethnography, it must pertain what Wolcott (2008a) calls "ethnographic intent". That is, it must seek to understand how being embedded within a particular cultural setting impacts participants' experiences of phenomenon through exploring shared patterns of belief, values, emotions, mental states, and behaviours from the emic perspective (Agar, 2008; Krane & Baird, 2005; Wolcott, 2008a). In this way, Agar (2008, p.12) provides the analogy of a guitar plectrum through which we may wish to conceptualise the ethnographic enterprise. This is the idea that as ethnographers, we "pluck" away "at the details of everyday life in several different locations". The locations that we pluck at (e.g., at the narrow end of the plectrum), however, are always inextricably attached to the socio-cultural contexts in which they are located (e.g., the broader end of the plectrum).

In further understanding what an ethnography is, it may be best thought of as a process and product (Krane & Baird, 2005; Wolcott, 1990). The processes of ethnography refer to what ethnographers do whilst conducting fieldwork, including how they collect and analyse data (Hammersley & Atkinson, 2007). Data collection entails a researcher participating:

> in people's daily lives for an extended period of time, watching what happens, listening to what is said, and/or asking questions through informal and formal interviews, collecting documents and artefacts – in fact, gathering whatever data are available to throw light on the issues that are the emerging focus of inquiry. (Hammersley & Atkinson, 2007, p.3)

The basic epistemology of ethnography, therefore, is simple: we enter the lives of participants in their natural settings and live alongside them (or at least endeavour to be around them for as long and closely as possible) collecting data in multiple forms in order to attain insight into their cultural and psychological realities (Atkinson, 2016). Implicit in this approach is that ethnography is open-ended,

emergent, and exploratory, in that researchers will enter a cultural group/setting of interest with preliminary questions they wish to answer. As they learn about the most important features of participants' experiences within this context, the questions and data that they seek to collect are transformed and refined (Hammersley & Atkinson, 2007). Agar (2008) refers to this process as "funnelling" in which the focus of our research topics gradually narrows as our understanding of the bigger picture becomes clearer.

Once data has been collected, another part of the ethnographic process is to analyse it. This includes interpreting:

the meanings, functions, and consequences of human actions … and how these are implicated in local, and perhaps also wider, contexts. What are produced are verbal descriptions, explanations, and theories; quantification and statistical analysis play a subordinate role at most (Hammersley & Atkinson, 2007, p.3).

Essentially, this is a method of cultural interpretation (Geertz, 1973; Wolcott, 2008a), whereby ethnographic data is transformed into an ethnographic product in which the researcher writes a rich, thick, and contextualised account of participants' experiences and behaviours. In assisting this process, ethnographers may choose to pull on theory in various ways. Whilst informed by induction, thus not aligning itself to a particular theoretical framework, the role of theory is important in ethnography, especially when seeking to understand and explain our data. In engaging in truly inductive ethnographic inquiry, therefore, we may wish to envisage different theories as part of our analytic toolkit; things which we can pick from when engaging in "sense-making" (i.e., trying to understand and explain segments of our data from the bottom-up) (Wolcott, 2005). In tackling questions of how and why things work as they do, selecting the most appropriate theories which possess the most "explanatory power" (Fetterman, 2010, p.7) can help us address what Agar (2008) calls "rich points" (Agar, 2008). These represent segments of our data that we do not understand and form the "raw materials of ethnography" (Agar, 2008, p.31).

4.3.1. Focused ethnography.

Traditionally, ethnography was associated with "ethnology"; a cornerstone of anthropology which was interested in the study of non-Western cultures and societies (Hammersley & Atkinson, 2007). This meant that early ethnographic work was almost always carried out "in a society very different to one's own." (Hammersley & Atkinson, 2007, p.1). However, in morphing to the demands of 21st century academic research, Wolcott (1999, p.42) recognises that ethnography has diversified, thus "has long since slipped out from under [its] anthropological tent."

One such form of ethnography that has emerged in recent times, and the type which was utilised in this project, is *focused ethnography.* This differs from ethnography in its traditional, anthropological sense in that rather than travelling to far-away places to study the rituals and events of unknown cultures, they are conducted by researchers who have a background knowledge of the group they are interested in and focus their investigation around distinct research questions in specific contexts (Knoblauch, 2005; Wall, 2015). In doing so, rather than exploring social groups, institutions and events in a more general sense, focused ethnographies are concerned with the actions, social situations, and interactions of social groups that are in some way familiar to the researcher (Knoblauch, 2005).

Furthermore, although it is true that insight may be gained through an intimate and long-term contact within a culture (with many ethnographies taking place over years), time constraints associated with modern academic research can make this difficult. What's more, Wolcott (2005, 2008) warns that long fieldwork periods do not guarantee that quality data is always collected. In dealing with the reality of time limitations, focused ethnographies are also typified by a shorter period of time spent in the field, which is compensated for by intense data collection and analysis (Knoblauch, 2005; Wall, 2015). Though focused ethnography slightly differs in its approach to collecting data, it still retains what Wolcott (1999) calls the "intent" of ethnography. That is, it remains focused on cultural understandings and descriptions and is dedicated to producing contextualised and rich data surrounding a groups values, beliefs, and knowledge (Wall, 2015).

Because of its explicit focus on culture, ethnographies are well-suited to research projects seeking to understand how being part of a social group impacts an

individual's personal and collective experiences of physical activity (Atkinson, 2016). As the aim of this project was to explore how participants' views and experiences of Tai Chi were located specifically within cultural context of a hospice's day therapy unit, the utilisation of a focused ethnography was considered the most appropriate qualitative approach in conducting this research.

4.4. Gaining Entry, Volunteering, and Legitimisation

Ethnographies begin with gaining entry into the setting that a researcher is interested in (Krane & Baird, 2005). The first step of this process is recognising and contacting a gatekeeper; individuals who possess authority over who can and cannot access a group in order to conduct research (Krane & Baird, 2005). Those who acted as gatekeepers in this study changed throughout the progress of the research project. Initially, the managing director of the hospice and Sue Ryder Research Governance Group (RGG) acted as the gatekeeper through reviewing the study protocol and granting ethical approval before access to participants was allowed. Whilst waiting for ethical approval to be granted, prior to collecting data, I sought to gain entry directly within the day-therapy unit of the hospice through taking up a volunteering role. At this level of entry, the hospice's day-therapy unit activities co-ordinator acted as the gatekeeper with whom I negotiated my access. After a DBS check and interview, we agreed that for a 2-month period before starting the research project (April 2016-May 2016) I would volunteer in the day-therapy unit twice weekly.

This role comprised of a variety of different tasks. For example, making light refreshments for patients throughout the day, helping to serve lunch, and taking part in activities such as dominoes, quizzes, arts and crafts, and gardening. A considerable aspect of this volunteering role was sitting and chatting to patients about everyday subjects like our families, hobbies, and interests. Because operating as a volunteer allowed me to show a genuine interest and care for patients' well-being, it helped me to develop a strong, trusting, and respectful rapport with people within the day-therapy unit (e.g., patients, therapists, nurses, volunteers, and the activities co-ordinator). In particular, the formation of these types of relationships with patients was essential if I was to expect them to talk with me about potentially sensitive topics in great depth and detail once fieldwork had begun (Jokinen,

Lappalainen, Meriläinen, & Pelkonen, 2002; Krane & Baird, 2005; Seymour & Ingleton, 1999). Volunteering in the day-therapy unit prior to data collection also helped me to become familiar with the cultural setting in which I was working and legitimise my presence in the field.

Following receiving ethical approval from the NHS South Central – Oxford B Research Ethics Committee and the Research Governance Group at Sue Ryder, the recruitment process began.

Critical reflection 1: Becoming part of the group (around 6 months in)

Upon signing out of the hospice for the day I started talking with the receptionist at the front desk. During this conversation she commented on how when she walked through the Day Therapy Unit she often noticed how I "seemed to fit right in down there". She also spoke about how patients seemed to warm to me and enjoy my company. Whilst this conversation occurred about half a year after I had "entered" the field, throughout my 2 and a half years at the hospice (including before, during, and after periods of data collection), these types of comments were made by other volunteers, nurses, therapists, and even patients themselves. Aside from being flattering compliments, I believe that they demonstrated the value of my volunteering role in assimilating into the day therapy unit and being able to form genuine bonds with patients who took part in this study. That is, being at the hospice and taking up a position in which I could be active in patients' care and well-being was something that I felt engendered their respect and trust. I wasn't perceived as "another researcher" or "a visitor to the hospice" but as an integral part of the day therapy unit team. I got the impression that this helped participants to feel comfortable in sharing challenging and private stories with me during interviews and informal conversations.

4.5. Sampling Strategy and Participants

Once entry had been gained and ethics passed, recruitment began. The sampling technique that a researcher uses, by and large, depends on the type, nature, and purpose of their research project (Etikan, Musa, & Alkassim, 2016). In this study, a purposive sampling strategy was used. Broadly speaking, this method

of sampling deliberately selects participants based on whether they possess certain qualities or demographics that will facilitate the researcher in attaining rich information surrounding their research question (Etikan et al., 2016). Whilst there are many different sub-types of this method of sampling (e.g., homogenous, typical case, critical case, total population, and expert), for this study, maximum variation sampling was used to recruit participants. The idea behind this type of sampling method is to try and understand a research question from as many angles as possible through selecting a diverse range of participants (Etikan et al., 2016). This was commensurable with my aims of exploring the views and experiences of Tai Chi from the perspectives of those with the varied disease types that typically make up the palliative care population. The inclusion and exclusion criteria for selecting such participants were as follows:

Inclusion criteria:

a) Service users currently attending the hospice as a day-case patient;

b) Service users already participating in Tai Chi sessions;

c) 18 years or older;

d) Able to understand, comprehend and communicate in English;

e) Able to give informed consent.

Exclusion criteria:

a) Service users who by the judgement of clinical staff at Sue Ryder are deemed too ill to participate in this study.

As the study progressed I recognised that some participants were more "culturally sensitive" than others, meaning that they were able to provide more articulate, richer, better informed, and therefore more insightful accounts and understandings with regards to their Tai Chi experiences (Fetterman, 2010; Marshall, 1996). These were usually participants who had previously been admitted to the hospice, thus had spent more time within the day-therapy unit than others. They were also overtly enthusiastic and willing to talk about their experiences of Tai Chi. In ethnography, these are called "key informants" or "key actors" and are often "excellent sources of information and important sounding boards for ethnographers"

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(Fetterman, 2010, p.50). Consequently, it was these types of participants who I selected to be interviewed in this project.

Because patients were admitted to the hospice on a rolling basis (typically for around 12 weeks) recruitment was ongoing throughout my time in the field. In recruiting participants, I worked alongside the physiotherapy team at the hospice in initially approaching current service users to enquire on their interest in taking part in this project. Provided they met the inclusion criteria, patients who declared enthusiasm in participating were provided with written details of the study (see appendix a). Before providing consent (see consent sheet in appendix b) patients were encouraged to take time to discuss their potential participation with their family, carers, healthcare providers, and members of the research team. In total, 19 participants who were diagnosed with various types of advanced, incurable and chronic diseases were recruited to this study (see table 2). They were aged between 50-91 years old (M=74.2) and consisted of 15 females and 4 males.

As recruitment was an ongoing process, decisions had to be made on when this process would come to an end. To assist with this, the technique of "data saturation" (O'reilly & Parker, 2013) was used. This type of saturation is very different to the type of theoretical saturation used by grounded theorists, in which categories derived through data analysis are explained, tested, and validated so that a new theory may be created (O'reilly & Parker, 2013). Rather, it is an iterative process of collecting and analysing data until nothing new is being learned and data starts to repeat itself (O'reilly & Parker, 2013; Smith & Sparkes, 2016). Therefore, when what was said during interviews and seen during participant observations ceased to provide any additional or novel insight into how participants viewed and experienced Tai Chi, a conscious decision was made to bring recruitment to an end. It is not the intention to claim that data saturation brought me closer to any kind of "truth" or "objectivity", rather, it meant that after my time collecting data in the field I felt confident in being able to paint an accurate and meaningful cultural interpretation with regards to the research aims and objectives.

Table 2: *Participant characteristics*

Psuedonym	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

Critical reflection 2: The challenges of recruitment

Most of what is written in the above section has painted recruitment to be a smooth process, however, this was not the case. Whilst recruiting participants in any qualitative project can be challenging, within a hospice setting there were various obstacles which presented unique difficulties. These included: (a) patients having other priorities (e.g., they would rather spend their limited time and energy around friends and family); (b) misunderstandings/apprehensions of the project (e.g., that it required them to visit the day therapy unit on more than one occasion each week); and (c) some patients simply not being interested in taking part in research (e.g., many told me they were "too old" or "too ill"). The first month and a half of this project was spent navigating these issues so that I could start data collection. In seeking to resolve some of these problems, I decided to visit the day therapy unit on two days (as opposed to one) each week. This allowed me access to a larger pool of patients who I would be able to approach to recruit for this project. I felt that this was particularly important if my sample was to representative of the palliative population more generally. Another technique that seemed to work well was to collaborate with the physiotherapy team in recruiting participants. Because they ran the Tai Chi sessions and assumed quite explicit professional roles within the hospice, I got the impression that patients felt more at ease when the project was initially introduced by them. These techniques proved to be effective, thus were used in recruiting participants throughout the remainder of the project.

4.6. Fieldwork and Data Collection

Fieldwork is one of the most characteristic elements of ethnography (Fetterman, 2010). It requires a researcher to fully immerse themselves in the group that they are interested in studying over a prolonged period of time so that they are afforded the ability to closely scrutinise the lived experiences of participants and understand how these are located within specific cultural settings (Fetterman, 2010; Sparkes & Smith, 2014; Wolcott, 2005). In doing so, fieldwork exposes researchers to the opportunity to understand, or *see*, culture at work through studying the shared social behaviours of a particular group in many different ways (Wolcott, 2008a). In understanding research questions in various different ways, thus producing an accurate, holistic, and contextualised cultural interpretation, it is necessary to rely on various data collection methods to provide us with different perspectives on the same phenomenon (Fetterman, 2010).

Accordingly, I adopted a "pluralistic" approach to data collection (Chamberlain, Cain, Sheridan, & Dupuis, 2011). This is the *integration* of multiple data collection methods across a research project (Chamberlain et al., 2011). Multimethod research (Chamberlain et al., 2011) enables different takes on a topic of investigation whereby different techniques illuminate and enrich one another (Williams, 2018). This produced a pluralistic data set which brought to life the complex, multi-dimensional, and embodied understandings of participants' experiences with Tai Chi in ways that may have otherwise proved inaccessible through using one method alone (Brinkmann, 2015; Chamberlain et al., 2011). With this in mind, data was collected directly from the field over a 6-month period (from July 2016-January 2017) utilising a combination of semi-structured interviews, participant observations, and informal conversations. Over the course of data collection, I attended the hospice and observed Tai Chi sessions roughly 33 times. This totalled around 200 hours spent in the field adopting the role of researcher and volunteer. A diagrammatic representation of the fieldwork process can be seen in figure 3 below:

Month 1	Month 2	Month 3	Month 4	Month 5	Month 6	Month 7	Month 8

Data Collection (x2 weekly):

Semi-structured interviews; participant observations; informal conversations

Volunteering (x2 weekly):

Immersed myself in the cultural surroundings of the hospice and formed relationships with patients
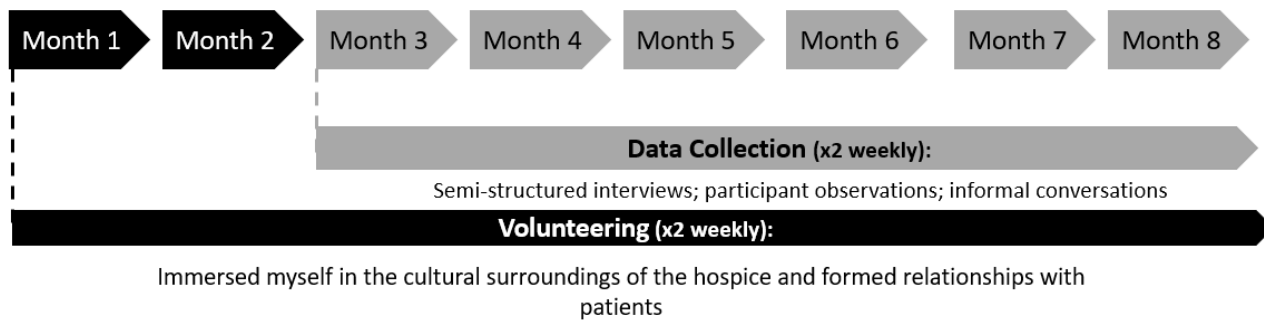
Figure 3: *The fieldwork procedure*

Critical reflection 3: More than just 'being there'

"Wolcott (2005) talks about fieldwork entailing much more than simply "being there"; we must not be deluded into thinking that by simply taking notes that we are doing ethnographic fieldwork. As researchers, we must be constantly "active" in the field through asking ourselves whether we are making the most out of the opportunity to gain insight into our research objectives and whether what we have set out to learn makes good use of the situation that presents itself (Wolcott, 2005). Next week I start with data collection and, having never conducted an ethnography before, I am a little apprehensive of how I am supposed to navigate this process. That said, I feel that following Wolcott's advice will be invaluable in guiding myself through what I expect to be a challenging and dynamic 6 months to ensure that I remain focused on participants' views and experiences of Tai Chi and how this related to their QOL."

Whilst this critical reflection was made at the start of my fieldwork, I used the concept of remaining "active" throughout the entire data collection process through constantly reflecting on what I was doing in the field and how I was doing it. In particular, I remained attentive to whether the questions I was asking and events that I was observing were appropriate in answering my research questions. In guiding this, Agar's (2008) analogy of a plectrum (see chapter 4.3) was useful in initially "plucking" at various aspects of participants' Tai Chi experiences. I then sought to ask questions that allowed me to further understand how these Tai Chi experiences were shaped by, and located within, the cultural context of the day therapy unit at the hospice.

4.6.1. Semi-structured interviews.

Qualitative interviews have been described in various different ways. Some have likened them to a relationship between two or more people (e.g., Randall & Phoenix, 2009), whilst others have compared them to journeys of discoveries that researchers embark upon with participants (e.g., Kvale & Brinkmann, 2009). Implicit within both of these definitions are that the coming together of the researcher and researched means that interviews are places where knowledge is co-constructed. Thus, the researcher cannot consider themselves, or the interview process, as a neutral data collection instrument that provides an objective and transparent insight into participants' experiences (Randall & Phoenix, 2009; Smith & Sparkes, 2016). Sparkes and Smith (2014, p.86) offer a general definition of interviews which resonates with these sentiments, that is, they:

> can be usefully described as a craft and social activity where two or more persons actively engage in embodied talk, jointly constructing knowledge about themselves and the social world as they interact with each other over time, through a range of senses, and in a certain context.

More specifically, ethnographic interviews take place within the field in which researchers have immersed themselves and spent considerable time forming respectful and ongoing relationships with participants (Heyl, 2001). As such, they contain various ethnographic elements including ethnographic questions that enable researchers to understand how participants experience and place meaning on events that occur within specific cultural contexts (Heyl, 2001; Spradley, 1979). Whilst various types of interviews exist (e.g., structured, semi-structured, or unstructured) (Rubin & Rubin, 2012), for the purposes of this study, semi-structured interviews were used.

Rather than a standardised set of questions that are asked chronologically, semi-structured interviews facilitate flexibility during the interview process through the utilisation of open-ended questions and a less rigid structure (Rubin & Rubin, 2012). Whilst semi-structured interviews are the most common data collection method in qualitative research, they are often selected without satisfactory justifications as to how or why they are appropriate to the phenomenon being studied (Culver, Gilbert, & Sparkes, 2012; Potter & Hepburn, 2005). The purposes for using

them in the context of this project was that they assisted in acquiring rich, in depth data surrounding participants' perspectives, experiences, feelings, behaviours, and emotions related to the research questions (Smith & Sparkes, 2016; Rubin & Rubin, 2012).

Whilst this much is true, Smith and Sparkes (2016) assert that our rationales for using interviews need to exceed the simple (and often-made) claim that they offer an opportunity to understand meaning and experience. In addition to this point, then, Smith and Sparkes (2016) propose that they can reveal the socio-cultural dynamics of everyday life through illuminating how culture and context can shape our experiences, values, and how we make sense of the world around us. In consequence, semi-structured interviews provided an appropriate means through which I could ask participants ethnographic questions (Spradley, 1979) that would be able to provide insight into how their views and experiences of Tai Chi were located within, thus affected by, the cultural milieu of the day-therapy unit at the hospice. For example, one question I asked participants was: "do you feel as though there are any unwritten rules that guide the Tai Chi sessions and, if so, what do you think they are/how do they affect your experiences of Tai Chi?"

Semi-structured interviews were conducted with 11 participants and aimed to explore their perspectives, experiences, emotions, and behaviours in relation to how taking part in a hospice-based Tai Chi program influenced their perceptions of QOL (Smith & Sparkes, 2016). Whilst it was initially intended to interview all participants at least once, for various reasons, this proved unfeasible. This was because the day's routine and structure at the hospice meant that on any given day, a maximum of 1-2 interviews could be conducted. Consequently, because ethical approval only gave permission to interview patients on site, interviewing all participants before they were discharged was practically impossible. What's more, due to illness and/or prioritising other commitments (e.g., meeting with nurses, doctors, and therapists during the day) it was sometimes the case that pre-arranged interviews with participants did not take place, with some patients being discharged before these could be re-arranged.

For those who did take part in interviews, the initial interview guide (see appendix c) comprised of a combination of "grand tour" and "mini-tour" questions (Rubin & Rubin, 2012) which related to participants' experiences with their physical,

psychological, social, and existential well-being since participating in Tai Chi. "Grand tour questions" formed the main scaffolding of the interview and invited participants to "show me around" their experiences of Tai Chi and QOL more generally (Rubin & Rubin, 2012). "Mini tour questions" represented the supplementary attentional and conversational (e.g., steering, confirmation, clarification, and elaboration) probes which allowed me to manage the interview and elicit further depth and understanding regarding participants' responses.

Interviews took place within a few weeks after their first Tai Chi session. 6 participants were interviewed a second time approximately 4-5 weeks later. For participants who took part in a second interview, questions focused on seeking clarification and allowing participants to elaborate on the accounts of their Tai Chi experiences given in initial interviews (see appendix d). Semi-structured interviews coincided with participants' weekly visit to the day-therapy unit and were conducted at a time that was most convenient for them. On average, interviews lasted 40 minutes and were audiotaped and transcribed verbatim. I listened back to and transcribed interviews as soon as possible after they had been conducted. This offered the opportunity to reflect on the interview guide and improve my ability as an interviewer (King & Horrocks, 2010; Wolcott, 2005). The critical reflections box below gives an example of how I used this technique throughout the research project to engage in a critical reflection of my skills as a qualitative interviewer in this context.

In qualitative research in sports, exercise, and health, however, there has been a disproportionate use of, and over-reliance on, semi-structured interviews as a method of data collection (Culver et al., 2012). Whilst the utilisation of semi-structured interviews has multiple advantages (some of which were covered above) their exclusive use can stunt the various other ways in which we may come to understand participants' views and experiences of hospice-based Tai Chi. This is because they privilege language as the medium through which knowledge is created (Bagnoli, 2009). Accordingly, they can often overlook the various non-linguistic and sensuous ways of knowing (e.g., what we hear, smell, touch, feel etc.) that are important to tap into if we are to understand the layered complexity of human experience (Bagnoli, 2009). In accounting for this, observations were used in tandem with interviews throughout data collection.

Critical reflection 4: Reflecting on my skills as an interviewer

Last Tuesday I conducted the first interview of my fieldwork. After listening back and transcribing, I don't think that it went particularly well. I felt that there were points in the interview where I missed opportunities to ask follow-up questions that could have given greater insight into what QOL meant to this participant. I also felt as though at times I spoke too much; I tended to nervously fill pauses with unnecessary or repetitive questions in ways that sometimes cut the participant off. However, these silences are often valuable as they allow participants the headspace that is sometimes needed to think about what they want to say, thus provide more in-depth and richer responses (Sparkes & Smith, 2016). I bared all of these reflections in mind before (and during) my second interview today. Specifically, I endeavoured to become more of an "active/creative listener" (Wolcott, 2005) in talking less, listening more, and being more attentive to the ways in which I could ask questions and probe in ways that could make the interviewee a better talker. This meant recognising pauses where participants were mid-thought, thus ensuring them the thinking space that they sometimes needed to expand on their answers in more detail. This greatly enhanced the richness and depth of conversations that we had in our interview today compared to the first. Whilst I recognise that there is still much room for improvement, these techniques form the basis through which I will be able to move forward and progress in my skills and confidence as an interviewer.

4.6.2. Participant observations.

Observations were used in this study through drawing on the various senses to observe, and then describe, how participants' experiences of hospice-based Tai Chi unfolded within the natural setting of the hospice day therapy unit (Kawulich, 2005; Sparkes & Smith, 2014). Gold (1958) outlined a continuum of roles a researcher may adopt when observing participants, including: complete observer, observer as participant, participant as observer, and complete participant. In this study, participant observations were utilised. These are a hallmark of ethnography and refer to researchers becoming an established member of the cultural group that

they are studying whilst simultaneously observing the interactions and dynamics that take place between participants within it (Fetterman, 2010; Kawulich, 2005).

In these ways, participant observations "interacted" with data collected in semi-structured interviews through exploring non-verbal behaviour (e.g., facial expressions, body posture, voice tone, and expressions of feelings), interactions between participants, and comparing what was said in interviews with what was seen in the field (Kawulich, 2005; Thorpe & Olive, 2016; Tjora, 2006). What's more, they afforded an "insider" status, granting me access to events and individuals from the "cultural inside" in ways that would not have been available to an "outsider" (Kawulich, 2005; Thorpe & Olive, 2016). This provided a contextual understanding of the culture of the day therapy unit at the hospice (see chapter 5.2) which I could then use as a backdrop through which to understand participants' views and experiences of Tai Chi (Sparkes & Smith, 2014).

The participant observations used in this study were overt in nature and took place during my twice weekly visits to the hospice. They provided me with the opportunity to take part in and observe participants during Tai Chi sessions. In guiding my participant observations during these sessions, I followed advice given by Spradley (1980). That is, I approached participant observations through a "funnel-like" approach that consisted of three levels of observations: descriptive; focused; and selective. This method allowed me to embrace the exploratory and emergent nature of ethnography through refining and narrowing my observations as I spent more time in the field and became attuned to what seemed to be the most important features of participants' engagement in Tai Chi (Fetterman, 2010).

Descriptive observations were fairly broad in nature and were used when first entering the field in order to answer the more general ethnographic question of "what was going on?" (Wolcott, 1994). To do this, I interchanged between what Spradley (1980) labelled "grand" and "mini" tour observations. The former focused on identifying the major features of the environment in which Tai Chi was located and performed. As a guide to forming these, throughout my initial field notes I strived to describe the following in relation to my research objectives: space (the physical layout of the environment); actors (who was involved in social interactions); activities (what related acts people were engaging in); objects (what physical things were

present); acts (behaviours exhibited by participants); events (sets of related activities); time (the timing and duration of events and activities); goals (what participants were attempting to accomplish); and feelings (what emotions were expressed) (Spradley, 1980). The latter are complementary to, but more specific than, grand tour questions. That is, they focus on probing in more depth what I had found during grand-tour observations. Once I had gathered a solid understanding of the general aspects of participants' experiences of Tai Chi I utilised *focused observations* to hone in on what had emerged as the most important features of it. Finally, *selective observations* were used which were highly focused observations of even smaller units of participants' experiences.

For example, during initial observations it became clear that Tai Chi consisted of various elements (e.g., music, mental imagery, choreographed movements) that were integral to participants' embodied experiences during sessions. Once I realised this, I used subsequent observations to focus on how their body responded to these different aspects of Tai Chi. These observations tended to look at obvious bodily features such as posture, facial expressions, and breathing patterns. I then further refined these observations through looking at how these physical experiences were negotiated within the cultural context of the day therapy unit. A visual example of how I gradually focused observations can be seen in figure 4.
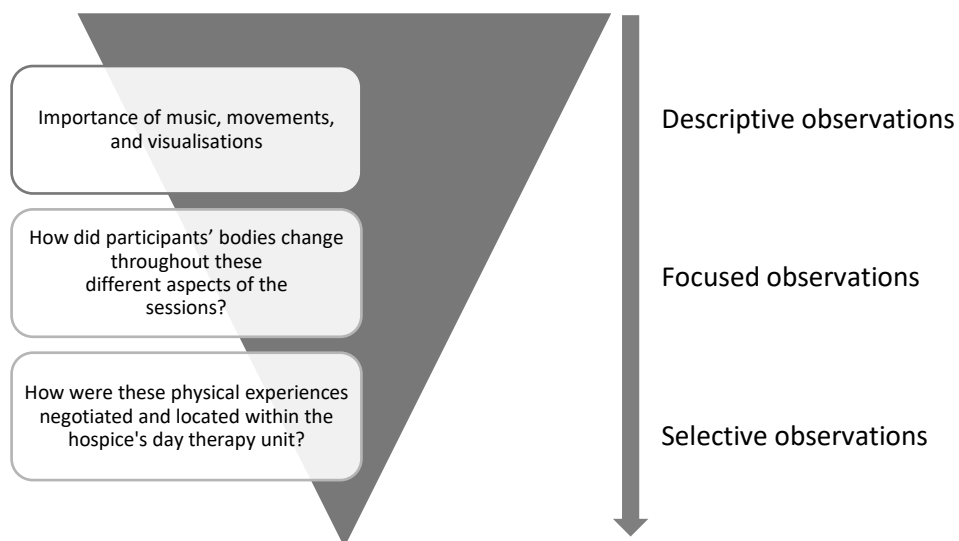
Figure 4*: An example of how the focus of participant observations narrowed*

Integrating these different forms of observations allowed me to go beyond merely describing the data and onto asking more stimulating questions that allowed me to explore the "how's" and "why's" of participants' experiences of Tai Chi (Wolcott, 1995). This process was akin to what Fetterman (2010, p.39) describes as "starting with a panoramic view of the community, then focusing in on microscopic detail, and then panning back out again but with insight into these smaller details."

Finally, Thorpe and Olive (2016) recognise that as a result of the "sensual turn" in the social sciences and humanities, researchers have questioned the visual bias that pervades much observational research. Epistemologically speaking, vision alone represents only one way of knowing, therefore there has been encouragement to use the different traditional (e.g. sound, touch, smell, and taste) and non-traditional (e.g. kinaesthesia, nociception, proprioception etc.) senses in order to create an embodied form of knowledge of our research questions (Thorpe & Olive, 2016; Stoller, 1997). In the earlier stages of my project, most of my participant observations focused on what I *saw* in the field. However, during the progress of the study, the sensual aspects of Tai Chi (e.g., how it felt to move the body, the sound of the music, the visualisations of imagery etc.) emerged as important aspects of participants' experiences. Therefore, in attempting to "research at the embodied level" (Evers, 2006, p.239), thus collect richer and more multi-dimensional data of participants' experiences of Tai Chi, in the latter stages of my participant observations I endeavoured to "think with [the] body" (Smith, 2016, p.269). This entailed recording participant observations of what I heard, smelt, and felt whilst taking part in Tai Chi sessions (see critical reflections box 7, p.145). It was hoped that through doing so, it would facilitate the development of an embodied empathy with participants through which I could better understand the multi-sensual ways in which they experienced Tai Chi sessions.

4.6.3. Informal conversations.

Informal conversations were also used as a method of data collection in this study. Informal conversations closely reflect what Hammersley and Atkinson (2007, p.70) label "normal social intercourse" (e.g., dialogue centred on ordinary topics of conversation) and what Spradley (1979, p.58) calls the "casual, friendly conversations" through which "skilled ethnographers often gather most of their data".

By definition, this approach to data collection is spontaneous, highly unstructured and renders the researcher less control over topics of conversation compared to formal interviews (Agar, 2008). Instead, it involves a variety of different types of talk and question-asking-strategies that an ethnographer may engage in whilst in the field. For example, ethnographers may sit and listen at length to participants talk at will about their interests or steer the topics of informal conversations in particular directions that are related to research-related questions (Agar, 2008).

Part of the art of fieldwork entails the ethnographer being attentive to the mundane, commonplace, and often taken-for-granted experiences of participants (Wolcott, 2008a). The spontaneity and normality of these conversations allowed me to tap into the everyday (and sometimes overlooked) features of participants' experiences of Tai Chi that they perhaps did not feel worth commenting on during semi-structured interviews (Sparkes & Smith, 2014). As a result, they acted as a fresh layer of data and provided an insightful and nuanced perspective of how participants perceived and attached meaning to their participation in Tai Chi within the hospice environment (Fetterman, 2010; Hammersley & Atkinson, 2007).

In the context of this project, informal conversations took place alongside engaging in informal activities with participants throughout my visits to the day therapy unit. Sometimes the content of such was general chat about current news stories, interests, hopes/aspirations, backgrounds, and family/friends. It was through these conversations that participants and I could naturally connect with each other outside of the realms of being a "researcher" and the "researched". Allowing each other into our lives helped to establish a common ground which further fostered the development of trusting and respectful relations. What's more, on many occasions these conversations were in relation to participants' views and experiences of Tai Chi. I used these opportunities to ask participants informal questions to clarify and expand on my understanding of what I thought I had learned in participant observations and interviews.

4.6.4. Field notes.

Participant observations and informal conversations were recorded in the form of field notes. Fetterman (2010, p.116) refers to field notes as:

the brick and mortar of an ethnographic edifice. These notes consist primarily of data from interviews and daily observation. They form an early stage of analysis during data collection and contain the raw data necessary for later, more elaborate analyses.

Various considerations were made when collecting field notes. These included when to record them, in how much detail, and ensuring that I did not confound descriptions of events that occurred in the field with my interpretations of them. The following paragraphs outline how I addressed these issues.

Whilst there is no "right" or "wrong" answer as to when to scribe field notes Hammersley and Atkinson (2007) and Agar (2008) offer some useful advice on this matter. They suggest that because our long-term recollections can easily diminish and become distorted, especially as we are continuously experiencing new events during our fieldwork, that we should write field notes as soon as possible after we have observed behaviours or interactions that are relevant to our research questions. Consequently, during this project, I chose to write field notes immediately after Tai Chi sessions had occurred. This consisted of taking a trip to a quiet and isolated place (usually the toilets) where I would write down what Agar (2008) called "condensed accounts". These were short entries of my observations, consisting of brief descriptive notes (e.g., key terms, phrases, and quotes) of events, actions, and social interactions that occurred with participants before, during, and after Tai Chi sessions. The real value of condensed accounts is when they are expanded on (Spradley, 1980). In consequence, when the day was over, I would spend considerable time in the dining area of the hospice expanding on my notes so that I was able to ensure that they captured the richness and detail of the day's events.

Furthermore, Hammersley and Atkinson (2007) recognise that it is unfeasible for a researcher to record every last detail of events that occur during participant observations, thus it is important for researchers to strike an equilibrium between the breadth and depth of field notes (Hammersley & Atkinson, 2007; Wolcott, 2008). For example, whilst we should be wary of avoiding "haphazard descriptiveness"; that is, irrelevantly describing things in our field notes just because they are there (Wolcott, 1994), one must also be mindful of providing too little detail. With this in mind, throughout the research project, I was conscious that when writing my field notes, I

prioritised topics and descriptions that were relevant and contributed to understanding participants' experiences of Tai Chi within the hospice setting. What's more, for things that I felt were particularly salient in understanding my research questions (e.g., the role of physiotherapists during sessions) I would spend more time and attentiveness in ensuring that I had described them "thickly". That is, describing what had happened alongside the social import/meaning of such (Geertz, 1973) in a way that was to help understand how the cultural values that were embedded within the hospice environment impacted participants' experiences of Tai Chi and QOL.

The final consideration that I felt relevant to recording field notes was the problem of attending to how I was impacting the writing process. Coffey (1996) recognises that fieldworkers are not neutral observers, rather, they are actors, authors, and writers within the field, therefore field notes are littered with their own understandings and interpretations. In addressing this, Babbie (1995) proposes that researchers should record separately what they "know" has happened and what they "think" has happened. The former refers to things such as "events, people, things heard and overheard, conversations among people, conversations with people and physical settings" (Tjora, 2006, p.434). The latter are analytic notes that include the researcher's interpretations and reflections of what they think their observations represent/mean. In dealing with this, I split my field notes into two columns (see figure 2). On the left were what Lofland (1971) labels as "running descriptions" and referred to what I "knew" had happened in the field. Working in an interpretive paradigm meant that these descriptions were ineluctably influenced by my own subjective interpretations (Corebetta, 2003), therefore it is not to say that these notes were "objective". Rather, they represented elements of my observations that I was confident occurred independent to my interpretations. On the right-hand side of my field notes was a column dedicated to my interpretations, or what I "thought" was happening in the context of the field/the meaning it pertained to participants. What's more, the right-hand column was also a section of my field notes where I could highlight what Agar (2008) called "rich points". These were instances throughout my participant observations where events occurred that did not make immediate sense or contradicted already collected data. Once rich points had been identified, I dedicated further interviews and observations in gaining coherence of these.

Place: Date and time:
Event:
Those Present:

Notes:	Interpretation (I)/Rich Points(RP)/General notes and thoughts(G):
Consider: - Space - Actors - Activity - Object - Acts - Goal - Feelings - Demographics	

Figure 5: *Field journal template*

4.7. Data Analysis

Ethnographic data analysis is a hugely time-consuming process concerned with "making sense" of data (Creswell, 2013; Dixon-Woods, 2003). Wolcott (1994) proposes three important and synergistic stages when coming to analyse and transform ethnographic data: (a) description (e.g., helping the reader understand "what's going on"); (b) analysis (e.g., seeking to describe the relationships between the essential features of the data-set); and (c) interpretation (e.g., making sense of data through drawing on concepts and theory). These were used as a general guide when analysing data in this project. This was through analysing data using different analytic techniques, including: thematic framework analysis (Ritchie, Lewis, Nicholls, & Ormston, 2013); thinking with theory (Jackson & Mazzei, 2013, 2018); and attending to outliers (Phoenix & Orr, 2017). The overall aim of the analytic process was to translate what was discovered during active involvement in the field into a written cultural interpretation of how participants viewed and experienced Tai Chi in the hospice setting (Thorne, 2000).

4.7.1. Thematic framework analysis.

Thematic framework analysis (Ritchie et al., 2013) endeavours to initially manage data into themes, make sense of it through deriving significant and recurring themes across the data-set, and then attempt to interpret and explain why these patterns occur. Through a continuous back and forth between data analysis/interpretation and raw data, it has a strong emphasis on ensuring the transparency of the analytic process by creating a clear audit trail of the linkage between raw data and the derivation of themes (Parkinson, Eatough, Holmes, Stapley, & Midgley, 2016; Smith & Firth, 2011). It is important to note that the themes derived from data analysis were not "discovered" and did not "emerge" from the textual data, rather, they were co-constructed between the researcher and researched. In Braun and Clarke's (2016a, p.740) words, themes were not treated as:

> ontologically real, discrete things, out there in the world (or the data), identifiable by researchers – like diamonds scattered in the sand, waiting to plucked-up by a lucky passer-by… this idea of discovery is deeply problematic to many qualitative scholars, who rather view themes as actively crafted by the researcher, reflecting their interpretative choices, instead of pre-existing the analysis. They are offered to the reader as a compelling and coherent reading of data, rather than (more or less) accurate identification of a decontextualized or pre-existing truth.

There were various reasons as to why the thematic framework approach was used as a guide in analysing data in this study. First, the wealth of data collected during interviews, participant observations, and informal conversations made the dataset for this project voluminous. The framework analysis method offered a systematic process comprised of interconnected stages which made it easier to manage big datasets so that a holistic picture of phenomenon could be accrued (Gale, Heath, Cameron, Rashid, & Redwood, 2013; Ritchie et al., 2003; Smith & Firth, 2011). Second, the constant back and forth between analysis and raw data meant that context could be preserved throughout the analytic process, helping to add depth and layers to the understanding and interpretation of data (Gale et al., 2013; Ritchie et al., 2013). This was particularly important given the salience of

cultural context in ethnography. Lastly, Gale et al. (2013) recognises that many data analysis approaches are associated with specific epistemologies, framework analysis, however, does not commit itself to any particular way of knowing. This meant that it could be used within the philosophical framework that underpinned this project.

Making sense of data from interviews and field notes was an iterative process that began during, and continued after, data collection. Whilst official data analysis using the thematic framework approach took part after my time in the field had ended, throughout data collection various intuitive analytical hunches were developed to help understand the most salient features of participants' views and experiences of Tai Chi (Parkinson et al., 2016). In this way, the data analysis process was "abductive", 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).

The procedure for analysis followed six interconnected stages, as follows:

1. *Transcription:* for framework analysis, the focus of transcription is not on the conventions of talk but rather on the content of what is being said (Gale et al., 2013), therefore an orthographic transcription was conducted through transcribing interviews verbatim.

2. *Familiarisation*: this comprised of immersing oneself in the raw data through reading and re-reading interview transcripts and field notes in order to gain an understanding of their substantive content whilst writing down initial ideas and impressions of the data in the margin. It also included re-listening to audio recordings of interviews so that the emotive tone of participants could be captured. This process was continued until I felt confident that I understood the depth and diversity of the dataset.

3. *Coding:* interview transcripts and field notes were worked through, line-by-line, openly coding elements that were related to participant's views and experiences of Tai Chi. The language used to code was kept as

close to that of the raw data as possible.

4. *Developing an analytical framework:* an initial analytic framework was
   created through the grouping of codes into categories and categories
   into themes based on their generality. Each of the themes and sub-
   themes were given provisional definitions in language that was
   grounded as close to the raw data as possible. Themes and sub-
   themes were accompanied by interview quotes and field note extracts
   which were representative of their definitions. In this project, two
   separate, yet related, frameworks were created: one for the objective of
   understanding participants' views and opinions of Tai Chi and another
   on the impact that Tai Chi had on perceptions of QOL. These
   frameworks were discussed with my supervisor on numerous
   occasions and subsequently revised until we were happy that they
   reflected the views and experiences of participants across the data-set.
   In this way, she acted as a "critical friend" who assisted in challenging
   my interpretations and construction of knowledge in relation to my data
   (Sparkes & Smith, 2014). Whilst this was instrumental in helping to
   think differently about how the data had been, and was being, moulded
   throughout the analysis and interpretation process, agreements shared
   did by no means result in findings being fixed and final. Rather, this
   technique was able to stimulate reflection on how the filters through
   which I viewed the world were affecting the way I conceptualised data
   (Smith & McGannon, 2017). So, whilst this process did not bring me
   any closer to the "truth", it certainly challenged me to re-think, thus
   develop alternative explanations and interpretations for my data.

5. *Indexing:* this process consisted of applying the thematic framework
   back to the data-set. This entailed going back through interview
   transcripts and field notes and applying the analytic framework back to
   them via highlighting parts of the text that aligned with the relevant
   theme within the framework. This process was continued until all
   relevant parts of transcripts could be confidently accounted for.

6. *Interpretation:* the data was then interpreted through recursively moving between, critically thinking about, and questioning the main themes that were sculpted during analysis and their relationship with related theory and concepts. This was achieved through a process of "thinking with theory" (Jackson & Mazzei, 2013, 2018) (see chapter 4.7.2). Though the notion of what theory is and how it is used within qualitative research is broad (Cassidy, 2016) its application in this project was a means through which a better *understanding and explanation* of participants' views and experiences of Tai Chi could be nurtured.

4.7.2. "Thinking with Theory"

Jackson and Mazzei (2013, 2018) argue that most qualitative data analysis is, in fact, not analysis at all. From their perspective, stages 1-5 of the thematic framework analysis technique (i.e., familiarisation to indexing) is more akin to organising and managing data, as opposed to actually analysing it robustly. These types of data analysis techniques, they argue, have become overly-focused/reliant on methods which do little work in the way of critiquing social life in all of its complexity (Jackson & Mazzei, 2013, 2018), characterising the types of methodolatry that has been problematised in qualitative psychology (e.g., Brinkmann, 2015). Drawing on the work of various post-modernist philosophers, therefore, they propose the technique of "thinking with theory" as a way of moving beyond the mere description and organisation of qualitative data (Jackson & Mazzei, 2013, 2018). I borrowed this concept in aiding the interpretation stage of data analysis in this project.

The notion of thinking with theory represents a "new analytic" within qualitative inquiry which entails putting theories and concepts to work in ways that allow us to think *with* our data in creative and transformative ways (Jackson & Mazzei, 2013, 2018). Central to the endeavour of thinking with theory is the notion of "plugging in". This is illustrative of the ways in which researchers pull on various theories and concepts and "plug" them into the data set as a way of opening up new understandings (Jackson & Mazzei 2013). In so doing, researchers can go beyond offering linear, thick descriptions or postulating about what participants' talk *means,*

and use theory to show *how things work*, thus push data past its "threshold" (Jackson & Mazzei, 2018). That is, as we plug in theory into our data and vice versa, we:

> push research and data and theory to its exhaustion in order to produce knowledge differently; in this way, we focus on the constitutive and generative aspects of texts. By refusing a closed system for fixed meaning (i.e., transferable patterns and themes generated from coding data with reductive language) we engage the threshold as site of transformation (Jackson & Mazzei, 2013, p.265)

In these ways, thinking with theory is not only an epistemological force which stimulates us to think about our data through multiple perspectives, but an ontological tool which can "undo" and "de-center" common-sense conceptions of our data, thus create new realities and ways of understanding our research topics (Jackson & Mazzei, 2018).

Consequently, this new analytic technique was chosen in this project because it encouraged the opening up of thought in ways that were able to shake me out "of the complacency of seeing/hearing/thinking" about my data in ways that I "always have, or might have, or will have" through using the thematic framework analysis technique alone (Jackson & Mazzei, 2013, p.269). By plugging texts into one another (i.e., co-reading data alongside/with theory), I was able to stimulate previously un-thought ways of relating to the data, thus avoid habitual, mechanistic, and dogmatic repetitions of unsurprising themes/understandings that were already present in the literature. Instead, I was able to seek novel explanations that were able to produce meaningful and useful insight to my research questions (Jackson & Mazzei, 2018).

Rather than following a prescriptive set of systematic procedures and methods, the process of thinking with theory in this study required intuition and a:

> a willingness to borrow and reconfigure concepts, invent approaches, and create new assemblages that demonstrate a range of analytic practices of thought, creativity, and intervention … We refer to our process as a "new analytic" to make way for the invention of something different that cannot be fully prescribed (Jackson & Mazzei, 2018, p. 717-718)

It was achieved through an emergent and unpredictable process of *doing* (Jackson & Mazzei, 2018). This was an abductive process (Blaikie, 2018, see previous sub-chapter) in which stages 1-5 of the thematic framework analysis was seen as a commodification (i.e., a bottom-up production of raw data), with robust analysis taking place in the interpretation stage through utilising the process of thinking with theory (i.e., a top-down process that used theory to ask questions of, thus explain data) (Jackson & Mazzei, 2013). Accordingly, after themes had been sculpted, I trawled back through my analytic frameworks whilst engaging in a process that can only be described as "reading-the-data-while-thinking-the-theory" (Jackson & Mazzei, 2013, p.264). In assisting this, I allowed myself to be inspired and stimulated by theories and concepts outside of the field of sport and exercise psychology, including sociology, health geography and neuroscience (Bazeley, 2009; Jackson & Mazzei, 2018). For example, I borrowed notions of bodily intentionality (Merleau-Ponty, 1962), affective environments (Andrews, Chen & Myers, 2014), therapeutic landscapes (Gesler, 1992; Doughty, 2013) and so on and so forth to ask different questions of my data. This allowed for a diffractive reading which Jackson and Mazzei (2013, 2018) have likened to going back through the data whilst imagining philosophers and theorists (Merleau-Ponty or Gesler, for instance) peering over one's shoulder and asking questions about it through different theoretical lenses. Plugging different theoretical and philosophical concepts into my analytic frameworks allowed me to cut into the centre of my data and put it to work in ways that pushed it past its threshold, thus generate new ways of coming to understand participants' views and experiences of hospice-based Tai Chi (Jackson & Mazzei, 2018). What's more, through weaving in theoretical and philosophical concepts during my presentation and discussion of findings throughout chapter 6-9, I also aim to convince the reader of my analytic interpretations of data contained in this thesis.

4.7.3. Attending to "outliers".

Braun and Clarke (2016b) propose that the analytical process does not finish after a thematic analysis has been conducted. Phoenix and Orr (2017) warns against the dangers of viewing it as such, as it can lead to what Sparkes and Smith (2014) argue as an "ironing out" of the nuances, contradictions, and complexities within a data-set. This is because "main themes" often overlook the importance of variation

within a data-set, thus results in an underappreciation of the heterogeneity of participants' experiences (Culver et al., 2012). This is particularly problematic in ethnographic analysis which is characterised by the researcher consciously searching for contradictions and inconsistencies in the data so that they can build an accurate and holistic picture of what is happening in research settings and why (Brewer, 2000; Thorne, 2000). Thus, using thematic framework analysis to only understand the common patterns that were shared between participants with regards to their views and experiences of hospice-based Tai Chi:

> misses other possible messages that individual stories might hold. Its use in isolation can also lead to an over-determination of the themes identified in the data, seemingly 'ironing out the pleats'. Indeed, core themes can often be underscored at the expense of variation, difference, and contradictions, and so lead the researcher to under-appreciate the fine-details of talk and the heterogeneity of experience. In light of such weaknesses, what is needed is an analysis that focuses on contradictions, nuances, difference, and the fine details of storytelling. (Smith & Sparkes, 2009, p.285)

Consequently, whilst there seems to be a tendency for qualitative researchers to acquire an understanding of commonality before diversity (McPherson & Thorne, 2006), Phoenix and Orr (2017) propose that identifying central themes may be the initial, as opposed to the final, stage of data analysis. A further analytical step that they urge researchers in sport and exercise to consider is how we deal with exceptional data, or "outliers". These are segments of text that deviate from the central conceptualisations/characteristics of themes, therefore represent the nuances and contradictions that are so important to understanding the diversity and messiness of human behaviour and experience (Krane, 2016; McPherson & Thorne, 2006; Phoenix & Orr, 2017). Through attending to and exploiting the messiness and complexity that outliers present, we can push our analyses to more sophisticated levels by digging beneath the periphery of our data so that we can view it from different, non-dominant perspectives that prompt novel ways of thinking (Bazeley, 2009; McPherson & Thorne, 2006; Phoenix & Orr, 2017). It is through doing this that we can bolster our confidence in, and rigor of, our findings (Phoenix & Orr, 2017). For this reason, the framework analysis was treated as the first step in the analytic

process which was followed by the search for, and integration of, outliers into the data as a means of providing another layer, or "texture", to the data.

This process was complex and comprised of various different techniques. One method that I used – after constructing my initial analytic frameworks – was to go back into interview transcripts and field notes and actively seek for data which contradicted and/or challenged main themes. At times this caused analysis to be an uncomfortable process. However, rather than discarding these bits of data because they did not conform to the main narratives of the thesis, I sought to integrate them within core themes through a process of juxtaposition and contrast. For example, whilst most participants spoke of the benefits that they experienced through the social elements of Tai Chi, for a couple of participants, this was seen as disruptive. Therefore, during the presentation of results, I placed these two different experiences adjacently to show the reader how the same events were often interpreted and experienced very differently by participants. Similarly, another technique that I used to integrate outliers into the write-up was through the utilisation of creative non-fictions (see chapter 4.8.2). These were used to *show* the readers the complexity, and sometimes contradictory nature, of participants' views and experiences of Tai Chi through inviting them into their lived and situated experiences of sessions.

However, there were times where I felt that integrating outliers into main themes caused their nuances and complexities to be lost; sometimes the above techniques felt more like paying lip-service to outliers, as opposed sincerely doing them justice. To address this, I decided to present some outliers in the form of case studies (see chapter 8) so that I could explicitly demonstrate the subtle, yet important, counter-themes that ran throughout the data. These did work in adding another layer to my analysis through demonstrating the heterogeneity and complexity of participants' experiences of hospice-based Tai Chi.

4.8. Representation

The stages of writing and representation are intimately intermingled with the analytic process; form and content cannot be divorced (Sparkes, 2002; Richardson, 2000). Thus, writing and representing the findings section of this thesis was treated as:

a method of inquiry, a way of finding out about yourself and your topic. Although we usually think about writing as a mode of 'telling' about the social world, writing is not just a mopping-up activity at the end of the research project. Writing is also a way of 'knowing' – a method of discovery and analysis. By writing in different ways, we discover new aspects of our topic and our relationship to it. (Richardson, 2000, p.923)

With this in mind, two forms of representation were used to present the empirical findings of this thesis: disrupted realist tales and creative non-fictions.

4.8.1. Disrupted realist tales.

All of the findings located in the following chapters are presented through what Sparkes (2002) calls a "disrupted realist tale". A traditional realist tale pertains 3 fundamental characteristics which, together, seek to disembody the author from the text as a means to foreground and give precedence to participants' voices (Sparkes, 2002; Sparkes & Smith, 2014). These include: (a) *experiential author(ity)* (e.g., the researcher evacuating oneself from the write-up); (b) *the participant's point of view* (e.g., empowering the voice of research subjects); and (c) *interpretive omnipotence (*e.g., explaining data through connecting it to theory) (Sparkes, 2002; Sparkes & Smith, 2014). These types of realist tales, when written well, are able to provide readers with compelling insights into the social worlds of participants (Sparkes & Smith, 2014). However, because conducting research in an interpretive paradigm means that data is the product of a co-construction between the researcher and researched, the notion of traditional realist tales are problematic. This is because it is impossible for authors to completely eradicate themselves from the production and presentation of data.

Disrupted realist tales, therefore, do work in illuminating the often taken-for-granted role that researchers play in the processes of data analysis and representation (Sparkes, 2002). They do so through requiring researchers to explicitly highlight their interpretive and analytic role in the construction of data through entering the text, thus "disrupting" the experiential authority of traditional realist tales. With this in mind, throughout chapters 6-9, I use extracts lifted from my reflexive journal in parallel with findings as a way to "disrupt" the realist tales I tell and reflexively demonstrate the analytic and interpretive thought processes that

guided the construction of themes. Aside from assisting me in positioning myself as a critically reflexive researcher, disrupted realist tales allowed me to *tell* the reader about participants' views and experiences of taking part in a hospice-based Tai Chi program.

4.8.2. Creative non-fictions.

It became apparent through data analysis, however, that the findings pertaining to participants' experiences of Tai Chi in relation to their QOL could not be done justice through simply telling the reader about them. That is, they seemed to iron out the complexity, messiness, and nuance of what it meant for participants to experience physical activity in the context of terminal illness, rendering findings too simplistic and lacklustre. Because qualitative data is often messy and "rhizomatic", Krane (2016) has called for researchers to reconsider the types of writing styles that are used to present our work. Indeed, Wolcott (2005) echo these sentiments by encouraging ethnographers to write with "panache". This means drawing on innovative literary techniques so that we may produce compassionate, empathetic, and participant-centred pieces that push the boundaries through which we (and our readers) may understand our data (Atkinson, 2016; Wolcott, 2005).

To supplement the disrupted realist tales provided between chapters 6 and 7, therefore, I draw on the genre of ethnographic creative non-fictions to *show* readers the complex, situated, and embodied ways in and through which participants experienced Tai Chi within the hospice setting. Ethnographic creative non-fictions are:

> a type of creative analytic practice (CAP) that tells a story which is grounded in research data and draws on literary conventions. Thus, when researchers speak of producing a creative nonfictional representation of ethnographic data, they are making it clear to the reader that their stories are not made up or wholly imagined but are based on empirical data systematically collected. 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, & Williams, 2016, p.59)

As well as those outlined above, the reasons for using ethnographic creative non-fictions in this study were as follows. First, it is believed that the findings of this project are potentially useful to a wide audience interested in palliative care research (e.g., academics, doctors, nurses, physiotherapists, occupational therapists, patients themselves etc.). However, traditional ways of presenting research findings (i.e. scientific and realist tales) are laced with academic jargon that are usually only intelligible to academic audiences, often resulting in them becoming lost in the literature (Smith, 2013). Because the stylistic conventions of creative non-fictions are easily understood and able to resonate with readers at a personal and emotional level, they are conducive to disseminating research to wide audiences in accessible ways (Smith, Papathomas, Martin Ginis, & Latimer-Cheung, 2013). Second, through rejecting the incorporeality of traditional methods of writing in academia, creative non-fictions allowed me to capture the various senses that were fundamental to participants' situated experiences of Tai Chi and QOL (Sparkes, 2016a). That is, they helped to provide "a deeply embodied, sensorial and relational account of human lives" (Smith et al., 2015) through recreating what participants felt, heard, touched, and saw whilst moving through spaces and interacting with others (Douglas & Carless, 2009; Smith et al., 2015). This presented a fruitful epistemological opportunity through which I could invite readers into the visceral and situated experiences of participants through allowing them to think with and through (as opposed to merely about) the stories I provide (Smith et al., 2013). By inviting readers into the text, it is hoped that these creative non-fictions are "good stories" which stir the imaginations of readers in ways that allow them to become "caught up in" the tales they read (Frank, 2010, p.145). In coaxing readers to participate and immerse themselves in these stories, I seek to abandon my role as a "declarative author persuader" (that was adopted in the telling of disrupted realist tales) and, instead, assume the position of an "artfully-persuasive-storyteller" (Barone, 1995; Smith & Sparkes, 2009).

4.8.2.1. Constructing the creative non-fictions.

The stories used in each of the creative non-fictions are based on the themes that were constructed through the thematic framework analysis. As such they are grounded in the data collected in interviews, observations, and informal

conversations and include real participant quotes, phrases, and interactions. In these ways:

> while the events that unfold in the story are "real", they do not follow in the precise order in which they were told or enacted in the data collected. Time is telescoped, and events are selected from the data to best represent the themes, plots, and theoretical points generated from the analysis of the data. (Smith, 2013, p. 135)

Each of the creative non-fictions presents a case of one participant's experiences of Tai Chi. These individual cases were chosen because they provided a good example of the common patterns that were found across the data-set for each specific theme. In constructing the creative non-fictions, tips and techniques proposed by Smith et al. (2015) and Smith (2016) on how to transform data into stories were used as a guide. This included drawing on a multitude of fictional writing methods including: developing plots and characters; writing evocatively and engagingly; dialogue; metaphors; similes; embodiment; flashbacks and flash-forwards; and thinking with one's body. The plot and scenes used in each creative non-fiction, therefore, were crafted in such a way that initially took the reader inside the homes of participants so that they could be given an intimate insight into the realities of each of their struggles with terminal illness. This was then followed by guiding the reader through the participant's lived experiences of Tai Chi within the hospice and how this related to their QOL. It was through doing this that I aimed to show (as opposed to tell) the reader about the deeply complex, sensuous, embodied, situated, and relational experiences of participants in (hopefully) evocative, compelling, and emotionally vibrant ways (Smith, 2013). I also attempted to use these stories as a way to *show* the theoretical and philosophical concepts that were laced throughout the data analysis section of this thesis in action.

An important note to make on these creative non-fictions is that because this project was grounded in constructionism, the stories presented in this thesis should not be read as grandiose statements of fact that are fixed and final. Rather, in line with the interpretivist nature of constructionism, and in the spirit of creative non-fictions, they have been deliberately left open to readers in such a way that invites and encourages them to critically reflect on their own understanding of Tai Chi's role

on QOL in patients with advanced, progressive disease. By leaving the story open it allows the reader to make their own decisions on what they take, or indeed, believe is possible to take, from them without having to conform to an absolute finding or theoretical interpretation proposed by the researcher (i.e., me).

4.9. Ethical Considerations

Ethical issues pervade the entire ethnographic research process (Fetterman, 2010) and rest on the basic assumption of "doing the right thing" (Palmer 2016). Therefore, throughout this project, ethical considerations were guided by a combination of "procedural ethics" and "ethics in practice" (Sparkes & Smith, 2014). The former refers to ethical approval sought from research ethics committees and/or institutional review boards prior to entering the field, whereas the latter is the notion that:

> Institutional ethical approval is just the first step, the basic entry point, into a long and complex process. One reason for this is that doing research in the field can throw up an array of unexpected, subtle and nuanced ethical dilemmas that RECs and IRBs cannot control or predict. It is to the complexities of ethical as a *process* in the field, where researchers necessarily have to engage in an *ethics of practice* (Sparkes & Smith, 2014, p.212).

Accordingly, before participant recruitment started, initial ethical approval was gained from the NHS South Central – Oxford B Research Ethics Committee (REC reference: 16/SC/0133) and the Research Governance Group at Sue Ryder (reference number: 2015-08). This represented what Sparkes and Smith (2014) label procedural ethics. As part of this application, as well as providing an overview of the rationale, purposes, and processes of this project, I addressed the potential risks and ethical issues that may have arisen whilst collecting data in the field.

Most of these revolved around researching a sensitive topic with vulnerable populations (e.g., factors influencing QOL in those with terminal illnesses). Conducting this ethnography meant that I was entering the lives of participants at a profoundly difficult time and expected them to provide great detail on highly personal experiences (Dickson-Swift, James, Kippen, & Liamputtong, 2007). Whilst for some this may be cathartic, for others, conversations could easily digress into upsetting

and distressing reminders of the threat of disease and prognosis (Mcllfatrick, Sullivan, & McKenna, 2006). I acknowledged, therefore, that there would have to be precautionary procedures put in place to prevent and deal with any potential distress that was caused through the conversations that I had with participants whilst collecting data in the field. These included working with the physiotherapy team at the hospice and my supervisor to ensure that the wordings of questions allowed me to explore the objectives of this study as compassionately as possible. Furthermore, during interviews, I was mindful to avoid inappropriately probing participants on sensitive topics and, instead, asked broad questions which allowed them the freedom to decide on how much or little they wished to divulge in regard to traumatic aspects of their illness. In instances where participants became uncomfortable with talking about sensitive issues, they were given the autonomy to change topic or reminded that they could halt the interview process at any point. If, after this, they needed further support, their named nurse (i.e., the nurse who looked after them during their stay at the hospice) would be informed, who would then be able to arrange appropriate support for the needs of this individual.

In addition to procedural ethics, in navigating the potential unexpected methodological and moral ethical issues that may arise whilst in the field, I adopted what Lahman, Geist, Rodrigues, Graglia, and DeRoche (2011) labels "culturally responsive relational reflexive ethics" (CRRRE). The notion behind this stance is that ethical issues are examined relative to the perspectives and expectations within our participants' cultural values and worldviews through addressing three "r"s. These include being culturally *responsive* through learning about, remaining sensitive to, and positively accommodating for, the cultural background of participants. Treating ethics as *relational* in that interpersonal relations between the research and researched are based on mutual respect, dignity, and connectedness. Being *reflexive* in regard to interactions between the self, context, and participants, and, when necessary, adapting in an ethical and moral way to ensure the preservation of participants' autonomy, well-being, and safety. It also includes being attentive to power imbalances and reflecting on how we can ensure the write-up of findings are transparent and intelligible.

The critical reflections boxes that have been, and will continue to be, laced throughout this thesis demonstrate reflexive and relational ethics in process. In

particular, a salient element of relational ethics was how I negotiated rapport with participants. As discussed in chapter 4.4, developing trusting, respectful, and balanced relationships with participants was crucial in collecting rich and detailed data about their experiences of Tai Chi and QOL. That said, this came with the potential danger of "seducing" participants (e.g. exploiting connections with them in order to gain good quality data) (Wolcott, 2005). To ensure that power imbalances such as these did not occur in this project, I ensured that I was transparent about my role as a researcher from the outset of the research process. Thereafter, when necessary, I reminded participants the primary reason as to why I was at the hospice and how I intended to go about my research. This was achieved through informal conversations in the field, as well as revisiting the aims and objectives of the study before commencing interviews with participants.

Finally, as an ongoing process throughout the project, it was necessary to constantly reflect on the issues of anonymity and confidentiality. Whilst the former refers to removing any identifiable information regarding participants, the latter deals with how we should manage and store private information that has been collected during our research (Olivier & Fishwick, 2003; Tilley & Woodthorpe, 2011). These assist in preventing "deductive disclosure", that is, participants being identified by other patients, health-care professionals, friends and family that were associated with the project (Kaiser, 2009). However, the quality of ethnographic accounts relies on thick and detailed descriptions of participants' experiences within particular cultural settings. This leads to a greater chance of identification and therefore presents the challenge of a balancing act on behalf of the researcher (Olivier & Fishwick, 2003; Sparkes & Smith, 2014). Not wanting to sacrifice the quality of this project for anonymity and confidentiality, or vice versa, I aimed to strike a balance between the two through replacing any obvious information that would lead to the identification of participants and setting with pseudonyms, as opposed to changing the content of transcripts and field notes in such a way that would compromise the richness of, or distort, findings. Through doing such, an accurate thick description of the context and participants' experiences could still be accomplished whilst minimising the risk of identification. Moreover, throughout the research process, all data (transcripts, participant ID spreadsheets, field notes, data analysis documents)

were saved in a password protected file on a computer that only the researcher could gain access to.

4.10. Rigor: Criteria for Quality Judgements

In order for qualitative research to be conducted at a level deemed of high quality, it is important for researchers to engage with contemporary methodological thinking (Smith & McGannon, 2017). There have been various viewpoints, thoughts, and debates amongst qualitative researchers with regards to the question of "what makes good quality research?" (e.g., Smith & Deemer, 2000; Smith & Hodkinson, 2009; Sparkes & Smith, 2009; Tracy, 2010). There is general agreement amongst scholars in this community that because the purposes and philosophical assumptions that underlie qualitative inquiry are so different to that of quantitative, that the criteria we use to judge such should be different. In consequence, Lincoln and Guba (1985) proposed the concept of "trustworthiness" as a pre-established, universal benchmark for judging the quality of qualitative work. This has been termed the "parallel perspective" (Sparkes & Smith, 2014) and includes issues related to credibility, transferability, dependability, and confirmability. The notion behind trustworthiness, as presented by Lincoln and Guba, is that the more techniques that we use for ensuring credibility, transferability, dependability, and confirmability, the better the quality of the research output. By this logic, if we use all of the techniques presented, we can perform the perfect qualitative study. Central to this perspective is the belief that through using these criteria we can judge the quality of *all genres* of qualitative research (Burke, 2016)

However, this idea has been problematized by various qualitative scholars (e.g., Burke, 2016; Sparkes, 2009; Sparkes & Smith 2009) and even Guba and Lincoln (1989) themselves. This is because the parallel perspective attempts to apply a universal and static list of quality criteria to all genres of qualitative research, meaning that it's seldom able to judge the quality of the various approaches within their own terms. For example, what makes a "good" ethnography differs from what makes a "good" poetic representation, therefore if we are to apply the same, rigid set of criteria to both it ends up in what Northcote (2012) likens to judging a good apple by the criteria of what makes a good orange. These arguments espouse the need for diverse and flexible criteria when we come to judge the quality of qualitative inquiry.

As an alternative, therefore, Sparkes (1998) proposed the "letting go" perspective to judging qualitative work. This is the notion that there can be no universal or fixed benchmarks to validate all types of inquiry as different criteria for validation are better suited to certain purposes, contexts, and forms of representation (Sparkes, 1998). In line with the philosophical underpinnings of this project, it adopts ontological relativism (acceptance of multiple, mind-dependant reality) and epistemological constructionism (knowledge is constructed) (Burke, 2016). Consequently, criteria should not be viewed as static, universal and permanent, but as a list of "characterising traits"; consensuses agreed by groups of researchers that may change over times and contexts (Sparkes & Smith, 2009). These lists of quality criteria should be used as a starting point that can inform the researcher of what they *might* do as opposed to *must* do across every context and occasion prior to conducting research (Sparkes, 1998; Gergen, 2014). The criteria and techniques that we select are done so on the basis of sensible decision-making and are rationalised through reasoned argument (Sparkes & Smith, 2009). With this in mind, based on work by various scholars (e.g., Smith & Caddick, 2012; Sparkes & Smith, 2014; Tracy, 2010) a list of the following criteria was used as a guide for producing high-quality research in this project:

- *Worthy topic:* The rationale given in the introductory chapters of this thesis demonstrates how this topic is relevant, timely, and significant within the field of physical activity/mindful movement, QOL, and palliative care.

- *Rich rigor* – The theoretical frameworks and constructs were appropriate for the purposes of the study. I also spent prolonged periods in the field (e.g., 6 months) collecting multi-method data from a purposefully selected sample.

- *Sincerity:* I remained constantly reflexive with regards to how I was impacting the research process (see critical reflections boxes) and maintained transparency over methods used and challenges faced.

- *Credibility -* I integrated multiple methods as a way to construct thick descriptions of participants' experiences and views of Tai Chi within the

context of the hospice.

- *Resonance* – Thick description allows readers the potential to make generalisations based on the transferability of findings. Furthermore, examples of naturalistic generalisations (e.g., findings personally resonating with readers) were found when feeding back results to participants and health care professionals at other Sue Ryder hospices which had conducted Tai Chi.

- *Significant contribution* – Based on the empirical data, I offer empirical, practical, and methodological implications of this project (see chapter 10).

- *Ethical:* I used a culturally relational reflexive ethics framework (Lahman et al., 2011) to deal with procedural and process ethical issues.

- *Meaningful coherence:* The methods and methodology were theoretically and philosophically consistent.

- *Exploiting exceptional data:* Exceptional and contradictory data was explicitly attended to through paying explicit attention to "outliers" (Phoenix & Orr, 2017)

In addition, the following criteria was selected from a list provided by Smith et al. (2015) to judge the quality of the ethnographic creative non-fictions presented in chapters 6 and 7.

- *Aesthetic merit* – It is hoped that the stories provided in the creative non-fictions were artistically shaped, aesthetic, and were open/invited the reader to give interpretive responses.

- *Expression of reality* – The creative non-fictions provide embodied, authentic, and contextualised accounts of participants' psychological, cultural, and social experiences of Tai Chi.

- *Evocation and illumination* – It is hoped that the stories presented in the creative non-fictions do work to emotionally and intellectually illuminate the findings presented in the empirical chapters 6 to 7.

- *Meaningful coherence* – The stories achieve their intended purpose through showing, as opposed to telling, the reader the empirical findings of this thesis in ways that stimulates novel and evocative understandings.

4.11. Summary

This chapter provided an outline of how I set out about conducting this PhD, describing the journey from process to product. The social constructionist philosophical underpinnings - which permeate every aspect of this project – were outlined and followed by a rationale and description of the methodological approach (i.e., a focused ethnography) that I used to guide the collection of data. I then outlined how I collected, analysed, and represented my data. Detail was given on how I navigated procedural and process ethical issues and suggested various criteria that readers may use to judge the quality of the work presented in this thesis. In the following chapter I set about painting a picture of the research context through providing the reader with a description of participants' lived experiences of advanced, incurable illness and the day therapy unit in which their experiences of Tai Chi were located. I also provide information on the hospice-based Tai Chi sessions that participants took part in during their stay within the day-therapy unit. The purpose of this is to provide a contextual backdrop through which the empirical findings presented in chapters 6 to 9 can be understood.

Chapter 5: Setting the Scene

5.0. Overview

The aim of this chapter is to follow the advice of Bazeley (2009, p.10) who wrote that in presenting the findings of qualitative research, it is necessary "to think about what the reader already needs to know before they can understand what you are now writing about". I have, therefore, divided this chapter into three sections. The first draws on empirical data from interviews and conversations in the field to describe the embodied and psychosocial adversities that participants in this study suffered from as a result of living with advanced, incurable disease. I draw on "the drama of fear and loss" (Frank, 2007) as a narrative template through which to tell these stories. Then, in line with the spirit of ethnography, the second part of this chapter provides a "cultural description" (Spradley, 1980) of the day therapy unit in which participants' experiences of Tai Chi were located. Accordingly, I seek to demonstrate how I tackled the ethnographic question of "what was going on?" through immersing myself in this cultural setting (in the roles of researcher and volunteer) over a period of just under 3 years (Wolcott, 2008). The third and final section of this chapter seeks to describe the Tai Chi intervention that participants engaged in whilst at the hospice. Through doing so, this chapter provides a contextual and cultural backdrop through which the findings in chapters 6 to 9 can be situated and enriched.

5.1. Living with Advanced, Incurable Disease: "The Dramas of Fear and Loss"

There are many different phrases and concepts that one may draw upon to describe the profoundness of what it means to be diagnosed with a terminal illness, including "major life crises" or "traumatic events" (Tedeschi & Calhoun, 2004). Unifying these terms is that the diagnosis of an advanced, progressive disease represents a significant, life-changing event that often shatters and fragments an individual's worldview and identity (Janoff-Bulman, 1992). A way of understanding participants' lived experiences of advanced, incurable illness is through drawing on the "dramas of illness" narratives that Frank (2007) proposes. These narratives of illness represent the different ways in which patients "play the part" of being ill and how in doing so they enact and tell stories which help themselves and others around them make sense of the world. One such drama that Frank (2003) presents is that of

"fear and loss". In speaking of such, he captures a big part of what it meant for participants in this study to live with terminal illness. That is:

> Illness precipitates a succession of losses: the loss of bodily capability and, for some, the loss of a pain-free life; the loss of partial or complete capacity to work; the loss of friends who are either scared away or whose agenda does not include visiting the ill and engaging in issues of illness; the loss of life as it was planned and the greater loss of a capacity for planning—the loss of a reliable future; and ultimately, the loss of life itself. These losses each instigate a cycle of fear as to where the losses will end. Illness has plenty of specific fears: fears of certain diagnoses; fears of surgery, treatment procedures, or side effects of treatment; fears of pain; fears of changes to one's body; and fears of recurrence. But standing over these, as a kind of meta-fear, is the fear of how bad it might actually get or the fear of where the bottom is. (Frank, 2007, p.388)

One such loss which all participants in this study experienced was that of physical functioning and their bodily capabilities. The progressive and uncontrollable nature of their illness meant that they noticed their bodies continually deteriorating (sometimes very rapidly) in ways that became all-consuming. In consuming their lives, these losses trapped participants in the physicality of "embodied time". That is, rather than functioning in relation to clock time which is structured by minutes, hours, and days, participants' physical decline meant that their sick bodies dictated the speed and manner through which they navigated and structured the world around them (Ellingsen, Roxberg, Kristoffersen, Rosland, & Alvsvag 2012; Ellingsen, Roxberg, Kristoffersen, Rosland, & Alvsvag 2015; Lindqvist, Rasmussen, Widmark, & Hydén, 2008, Toombs, 1990). This was problematic because functioning in the embodied rhythms of this inner time plagued participants with fleshy and corporeal suffering such as pain, fatigue, nausea, and breathlessness which made their lives seem slow, protracted, and arduous (Buetow, 2004; Gergel, 2013). Giuliani, Piredda, Ghilardi, and Marinis (2015, p.415) have described this type of suffering as the body "surrender[ing] itself to the disease", something which left participants in perpetual states of discomfort and distress.

One type of loss that trapped participants in these states was, in the words of Frank (2007, p.388), the "loss of a pain-free life". In the preface of this thesis, Hitchens uses the word "lacerating" to describe the pain that he experienced as part of living with advanced, oesophageal cancer. This word evocatively captures the embodied essence of what pain was – or at least had the capacity to be - for participants in this study. For example, the following extract from my field notes demonstrates the observable effects that disease-related pain had on Stan, a participant who had advanced prostate cancer:

> "Arggh", I heard from across the side of the room. I looked up and over to see Stan, with his face scrunched and lips pursed as he scuffled his bottom from one position to another struggling to find a comfortable position in which he could sit. It was obvious that unbearable pain in his prostate was making it almost impossible for him to achieve this. He could hardly sit still for more than a few seconds at a time. After negotiating with his body and the chair for a few moments, he ended up in what still looked like an uncomfortable position, using his arms on the rests of the chair to perch himself sideways as he leant his body weight onto one buttock as to relieve the pressure on his prostate. [observational field note]

For some participants, the loss of a pain-free life and the never-ending states of distress that this caused them created a sense of hopelessness. In these ways, they entered "chaos narratives" (Frank, 1995) in which they told stories of how they inhabited an irreparable "chaotic body" (Sparkes & Smith, 2013, p.84). In this narrative, being stuck in constant pain meant that they saw no way of how life was going to get better, thus resigned themselves to a state of giving up. The following conversation I had with Elizabeth, a patient with metastatic lung cancer, demonstrates this:

> Before the Tai Chi session started I took time to go and speak to Elizabeth. The truth be told, she looked fed up and tired.
>
> "How are you today, Elizabeth?" I asked.
>
> "I'm a bit fed up today."
>
> "Is it one of those days?" I naively asked, when she replied:

"It's been one of them months. I'm just exhausted and in pain, all across my chest and my shoulder is really painful. I'm just completely fed up. I wish I could just shut my eyes and go for a long sleep and not wake up again." [informal conversation]

Similar sentiments of giving up were also shared by Gloria, who midway through talking about the impact of her illness on her QOL told me: "I've had enough, I've really had enough, I feel as though I have" [interview 1].

As well as the intrusions of physical pain, feelings of fatigue also undermined participants' QOL through taking over and trapping them within the uncomfortable realm of embodied time. Adding to the list of losses presented by Frank above, therefore, this demonstrated how participants in this study had lost the privilege of a fatigue-free life. This was described as a state of "constant tiredness" [Michael, interview 1] and feeling "tired all the time" [Rachel, interview 2] and was a source of frustration because it denied participants the vigour that was required for them to do things at paces which they had always enjoyed. For example, Stan spoke about how progressive fatigue took over his life because it caused him to be:

exhausted a lot of the time. I wasn't at the start but as it's got worse, so the *exhaustion has taken over* … if I want to do a job, I've got to get all the tools and everything lined up one day so I can do it the next day, I can't do it all in one go and I find that frustrating… I like to get out and see people and do things. If I can help anybody I will, but I haven't got the energy to like climb up ladders any more, this sort of thing. I get a lot of satisfaction from helping people. [interview 1, emphasis added]

Progressive physical and illness-related losses denying participants the opportunity to engage in tasks and activities that they loved doing was ubiquitous. For example, Gloria suffered from breathlessness which prohibited her from conversing with others:

It's [the breathlessness] worse now than when he first told me that [I was terminally ill]. I just thought I was getting short of breath, but I mean I'm on oxygen all the time more or less now … I can't breathe. You see, I'm talking now a lot and you can probably tell I'm getting more and more breathless. I can't [AB: Just go at your pace] I just can't do it. [interview 1]

Similarly, Roy – once a keen traveller and lover of the outdoors - spoke about how his breathlessness and decline in mobility meant he was unable to go on country walks:

the only thing is it's the lack of mobility, cos I've no problem with walking but I can't breathe when I am walking so therefore my mobility is actually cut down quite drastically, which initially it was on hills and stairs, but now I'm even finding it difficult walking distances on flat … I like meeting people, I like going to places, I like doing all sorts of things and when you're sort of limited to not being able to do these things, it's a bit much. [interview 1]

Because the physical losses associated with their illnesses often controlled what they felt they were able to do, it confined participants to living in embodied time whereby their bodies dictated the spaces in which they could operate and the pace at which they could operate within them. In consequence, there were tensions between trying to function through inner/embodied time in a world where others functioned via clock time. This was because the pure, visceral distress that participants' diseases imposed meant that everything about their worlds became fixated on the discomfort of their bodies in the present moment. Thus, clock time lost its structural impact and importance which sometimes made it hard for participants to meaningfully engage with other people (Ellingsen et al., 2013). Ellingsen et al. (2013, p.171) have spoken about how this disharmony can cause "an offensive feeling of getting behind and being an outsider". Indeed, the embodied losses related to participants' diseases meant that they struggled to keep up with a fast-paced world, progressively shrinking their lives to the four walls of their houses. In consequence, they felt sequestered from everyday life which resulted in feelings of social isolation. For example, Rachel reflected:

R: I aint really got a life because I stopped doing everything, because of my illness

AB: What kind of things?

R: … I used to like going out, I used to like socialising and that was one of me main things, going out with me friends and things like that. But because of me illness now, I've cut a lot of people off. So I don't do it anymore… relationships, things like that. It's just non-existent… *Sometimes I might not*

see anyone for days, you know, so it can be quite lonely really… it's depressing. [interview 1, emphasis added]

Similarly, Judy alluded to feelings of social isolation that were attributable to "the loss of friends who [were] either scared away or whose agenda [did] not include visiting the ill and engaging in issues of illness" (Frank, 2007, p.388). She also spoke about how this was made worse by the fact that her illness had stripped her of the right to drive. In an interview she told me:

when I was first diagnosed, and the prognosis was so bad, everyone was determined they were going to see me cos they thought I was going to be dead tomorrow, but of course, you can't keep that up for long cos everyone's got their own lives to live, so that's gone off quite a lot now. I've still got friends who keep in touch but not, you know, like they used to … I can't drive, and that's the worst. Cos it [the cancer] went to my brain I'm not allowed to drive and I've had to give me car away and I loved my car and I loved the feeling if I just jump in it and go anywhere, so that's the main, if anyone was to ask what's the worst thing about it, it's losing ability, losing the right to drive, not the ability to drive. [interview 1]

Whilst like Rachel and Judy many participants suffered from a social loneliness that resulted from losing social networks, it was also the case that many suffered an emotional loneliness. That is, even in the presence of others, participants still felt a sense of being alone because they felt that "healthy people" could not relate to what they were going through (Ettem, Derksen, & van Leeuwen, 2010). Consequently, it came across as though many participants felt that they inhabited a separate and incommunicable world to those who surrounded them. Rachel spoke of such in an interview by saying:

R: I feel that people don't really understand me. You know, they ask me how I am and all that, but they don't really understand what I'm going through

AB: Because they haven't been through it kind of thing?

R: Yeah. [interview 1]

In line with Frank's narrative of the "drama of fear and loss", almost all participants spoke about how the losses outlined above culminated into multiple

fears and worries. From my time immersed with participants in the field, I learned that it was not death itself that they feared. For them, death was immaterial; it was something we must all do. However, it was the *process of dying* that was the source of their apprehensions. In the words of Jane: "you just get yourself a bit concerned: how will it be?" [interview 1]. For example, many recognised that declining physically meant that they were at risk of dying in excruciating pain, as showed in Judy's apprehensions of the dying process:

> [I have] no fears of dying. The only thing I would be apprehensive about, and hopefully they won't put on me, is pain. I do not want to be in pain and I can remember when my mom died of cancer, I can remember her riling on the settee and saying: "I'm not afraid of dying, I'm just afraid of being in pain". [interview 1]

These worries represent the "meta-fear" of illness presented by Frank (2007). That is, the unknown and unpredictability of living with advanced, incurable disease created an overarching fear in participants; "the fear of how bad it might actually get or the fear of where the bottom is" (Frank, 2007, p.388). As well as the personal impact of the dying process, participants also worried heavily with regards to the effects that death and dying may have, or already was having, on their relationships with loved ones. The fear of impending and eternal separation from family who depended on them was something that played on their minds and caused considerable distress. For example, in an emotional interview with Rachel I asked her if there was anything that she feared about the future to which she responded:

> R: I don't wanna die.

> AB: Does that worry you?

> R: It does, cos I nearly died twice this year and just being so close to death and seeing how it upsets me sons [starts to cry], I wouldn't wanna leave them, cos they rely on me too much and I get frightened. [AB: Are you alright? Do you want to take a minute?]. No, I'm alright. I get frightened of the thought of having to leave them and how it'd make them feel. [interview 1]

Furthermore, many participants worried that as their disease progressed, and they gradually lost the ability to physically function and look after themselves, that they would become a burden on other people. For example:

AB: looking forward to the future, is there anything that worries you or any concerns that you have looking ahead?

J: … I would not want to be with them [my children] in a bad state of cancer, cos you don't know what the final stages of the cancer, how it's going to affect you … I wouldn't want to be a burden. And I don't think I really have a right to expect, you can't take for granted, it's not a right for children to take you on at the end and my idea is to come, if I can in, into a hospice at the end *… you just don't want to be a burden,* not that you, I don't think you would be a burden, but I don't think you can land it, you mustn't land onto people to expect them to do it, you know. As long as I mean as I was taken care for and they came to see me and visit me that would be fine, which they would do, which I know they would do, you see. [Jane, interview 1, emphasis added]

The fear of being a burden was serious and exhausting. Quoting Alphonse Daudet, Frank (2007) writes: "suffering is nothing … it's all a matter of preventing those you love from suffering". Indeed, participants in this study seemed more concerned about, and went to great lengths in, hiding the severity of their condition as a way to protect their loved ones from suffering. Hypervigilant in not being a burden to others, they engaged in what Frank (2007) calls the "drama of emotion work", that is, *concealing* their illnesses from others so that it did not seem as though "anything dramatic [was] taking place" (p.387). For example, in an interview with Doreen, she told me how her illness frightened her "but when me son asks me how I am I tell him I'm fine. Everything's rosy [smiles], cos I don't want to worry him, you see" [interview 1]. Similarly, Janine told me:

I do tend to cover things up when I'm talking to my lads, cos they natter over me and I don't want them to. I know its human nature, but, erm, yeah. Yeah, I do cover up. Sometimes I let them know what it's like and then other times I don't… It's not easy, no. [interview 2]

This emotion work was a way in which participants altruistically protected the feelings of their loved ones. Whilst they felt that this was a necessary process, this act was tiring and emotionally isolating.

The myriad of physical and psychosocial fears and losses that participants experienced left many feeling shattered, confused, and vulnerable. Anxiety and depression, therefore, were commonplace. For example, Rachel spoke of how an amalgamation of traumas she had experienced as a result of her illness and co-morbidities in the last year resulted in bodily anxieties that caused her frequent and unmanageable panic attacks:

> I were diagnosed with COPD 7 years ago, but the last couple of year it's got worse, so erm I've been in hospital 5 times in the last year and all because I had chest infections, but they've all resulted in other illnesses such as shingles, pneumonia, chicken pox, erm and heart attack and now it's because of all that, it's making me have panic attacks. So, when I can't breathe I panic, so my worst thing now is me panic attacks basically. [interview 1]

The multiple fears and losses that pervaded participants' illness narratives undermined various domains of their QOL (e.g., physical, psychosocial, and existential). In endeavouring to address their needs, patients were referred (either by their GP or district nurse) for specialist care at the day therapy unit of a local hospice. It is to the cultural context of this hospice environment to which I now turn.

Critical reflection 5: Trying to understand the "other"

The other week I went for an ultrasound scan for a problem related to my heart. Never before have I ever felt like an "ill" or "unwell" person, however, this whole experience somewhat introduced me into this unfamiliar territory. The thought of having such a vital part of the body not working properly almost made me feel slightly detached from a previously existing identity of being "healthy" – one that you never really pay attention to until it is challenged. I also spent weeks before and after my scans riddled with anxiety and worry at the prospect of something being terribly wrong. I couldn't concentrate and, whilst perhaps illogical, found it difficult in committing to or planning anything in the near future. I remember not daring to even mention it to my Mom through fear of worrying her. The reason that I include this entry into my reflexive journal is because throughout the entire project I have grappled with the question of how I am ever supposed to understand participants' lived experiences of illness when I have never been ill myself. Whilst it ended up that nothing was wrong with my heart, the mere *thought* of having a serious condition was shattering. Whilst I make no claim that I was ever able to truly enter the worlds of the participants in this study, reflecting upon this whole ordeal exposed me to (in very immediate and visceral ways) the vulnerabilities (especially psychological) that people with terminal illnesses may feel. It gave me a sort of first-hand introduction into their worlds; something that I used to try and empathise with, thus be able to capture during writing about, the profoundness of living with a terminal illness.

5.2. Day Therapy

Integral to any ethnographic piece of work is an understanding of how experiences are located within specific cultural settings. Upon entering the field, therefore, my first aim was to learn about the culture of the day-therapy unit at the hospice. This would provide me with a cultural backdrop through which I could understand the ways in which participants' views and experiences of Tai Chi were located within this environment (Spradley, 1980; Wolcott, 2008). In particular, I was interested in the inner workings of the hospice, that is, the implicit routines, rules,

social norms, and ethos through which it functioned (Krane & Baird, 2005). I initially achieved this understanding through immersing myself within the cultural setting of the day therapy unit (in the form of a volunteer) for 2 months (April 2016-May 2016) prior to collecting data. This acted as somewhat of a "survey period" in which I was able to learn the basic ways in which the cultural group within the day therapy unit functioned (Fetterman, 2010). To supplement my understanding of the cultural context that I gathered during this 2-month period, once ethics were passed, I used initial interviews and conversations with participants to further learn what being embedded within the culture of the day therapy unit was like from the "emic" perspective. In these ways, I used Wolcott's (2008) advice of "experiencing, enquiring, and examining" as a way to answer the fundamental ethnographic question of "what was going on?". *Experiencing* refers to how we understand cultural spaces through participant observations whereas *enquiring* is a more interview-styled technique of information-gathering which requires an ethnographer to converse with participants in formal and informal settings. *Examining* is about how one may use archives, documents, and other pieces of information that have already been produced to comprehend the inner workings of the context that we are located (Wolcott, 2008).

Critical reflection 6: "Unlearning" the culture of the day therapy unit

By the time that I came to write this chapter of the thesis, I had been at the hospice (in the capacity of volunteer and researcher) for just under 3 years. Whilst I understood that this level of enculturation put me in a great position to write convincingly and confidently about the cultural context of the day therapy unit, I also felt the need to try (as best as I could) to "unlearn" various aspects of the environment that I had become accustomed to. This was in an attempt to ensure that I did not miss the mundane and often taken-for-granted aspects of culture that can easily be forgotten about or overlooked after being immersed in a social setting for so long. In doing so, I found it useful in referring back to early entries of my reflexive journal in which I had quite extensive notes of my initial impressions of the hospice. I feel as though this allowed me to refresh my mind of the fundamentals of the cultural context of the day therapy unit and write about them with the added confidence that being immersed in the setting for so long had enabled.

In drawing on these three techniques I learnt that the day therapy unit had an unmistakeable ethos which was captured in the hospice's maxim of "incredible care". This encapsulated many different things that were deemed necessary to provide patients with the highest standard of care so that they could, in the words of Dame Cicely Saunders, "live until [they] died" (Saunders, 2001, p. 432). One such factor that was important in contributing to this was placing patients at the centre of the entire care process by identifying, and subsequently working in relation to, their needs, aspirations, and preferences. The cultural value of patient-centeredness was propagated across a wide range of hospice advertising materials, including in their newsletters, websites, and pamphlets within the hospice itself. For example, in describing the care services offered by the hospice on their webpage, the hospice notes how they provide "advice, treatment and support for our patients and their families through a range of services *so that people can have choice and control over how and where they receive their care*" (see figure 6, emphasis added).

Indeed, the notion of patients being put at the centre of the care process was something that became obvious and was very quickly reaffirmed through the routines that I observed as part of immersing myself within the day therapy unit. For example, at the start of each day, volunteers, nurses, doctors, physios, and occupational therapists all gathered in staff briefings so that they could recap on what patients were to be expected at the day therapy unit on that day and give an up-to-date breakdown of their needs. In these meetings, I was struck by how well all members of the day therapy unit team knew each patient. In particular, it was the norm for them to - sometimes at great length - go out of their way in getting to know their patients as people. As well as being aware of their illness-related symptoms so that they could take care of them medically, they also had an in-depth knowledge of their interests, hobbies, likes and dislikes, living arrangements, relationships with family members, and so on and so forth. This encyclopaedic knowledge that was shared between team members allowed them to achieve the ultimate goal of palliative care: adopting a multidisciplinary and holistic approach in addressing patients' multifaceted needs.

Figure 6*: Care services offered by the hospice lifted from their webpage*

Another example of this patient-centeredness in practice was how nurses and doctors spoke to patients about treatments, therapies, and care plans in a non-compelling manner. Instead of being told what they *must* do, advice and information was provided to patients and framed as what they *may* do. In this way, in line with their ethos, patients were given control and autonomy over their healthcare. This focus on what one may (as opposed to must do) permeated other routines at the hospice, including what activities they did or did not engage in, what they chose or did not choose to eat at lunch, and whether they came to the hospice at all. What patient-centred and holistic care meant in the context of the day therapy unit was further enriched through the comparisons that many patients made between the care they received at the hospice and the hospital. For example, Christie reflected:

C: The nurses [at the hospice] are absolutely brilliant cos you get to know them and you get your one particular nurse and they know you so well … [at the hospital] I feel as I've been dehumanised by a case of "here's an appointment, go there", "here's an appointment go there", "here's a CT scan, go there". And they get you so that your own life, however much, it doesn't seem to matter, doesn't matter to hospitals, you know, "you will go here at a certain time", "you will be there at a certain time" and they dehumanise you

AB: Do you get that here? What's the difference between [hospice name] and the hospital then in terms of that?

C: It's entirely different here. You know, "do you want to come talk?", you know, "have you a minute", "it'll do when you've finished your game", "do you want a cup of tea?" … it's more caring, it's more human. [interview 1]

In these ways, the ethos that permeated the day therapy unit at the hospice was in line with the aims of palliative day care more generally. That is, to reaffirm and facilitate patients' autonomy in ways that foster dignity and self-worth (Corr & Corr, 1992; Spencer & Daniels, 1998). An analogy provided by Hockley and Mowatt (1996) perfectly captures how the cultural value of patient-centeredness played out in the day therapy unit. In many ways, it was akin to moving patients into the driving seat of a car because:

being a driver of the car gives one the freedom to choose where to go and when to stop. A terminal illness doesn't need to be a passive acceptance of being told what to do because of the inevitable. Our responsibility as health workers in a day hospice is to enable people attending the centre to experience a feeling of importance and self-worth in their lives. The day hospice team becomes the co-drivers; enabling the patient, 'the driver', to make choices about what they would like or like not to do. The rehabilitation team within a day hospice needs to be 'alive', 'alert' to the journey that the patient is on. (Hockley & Mowatt, 1996, p.21)

Another cultural value that underpinned the day therapy unit – and represented the ethos of palliative day care more generally – was the notion of providing "a day out for the patient and a day off for the carer" (Fisher & McDaid, 1996, p.8). For example, on the hospice's webpage it speaks about coming to the

day therapy unit to enjoy various activities and "a chat over a cuppa with people in similar circumstances, whilst giving carers a break too" (see figure 7).
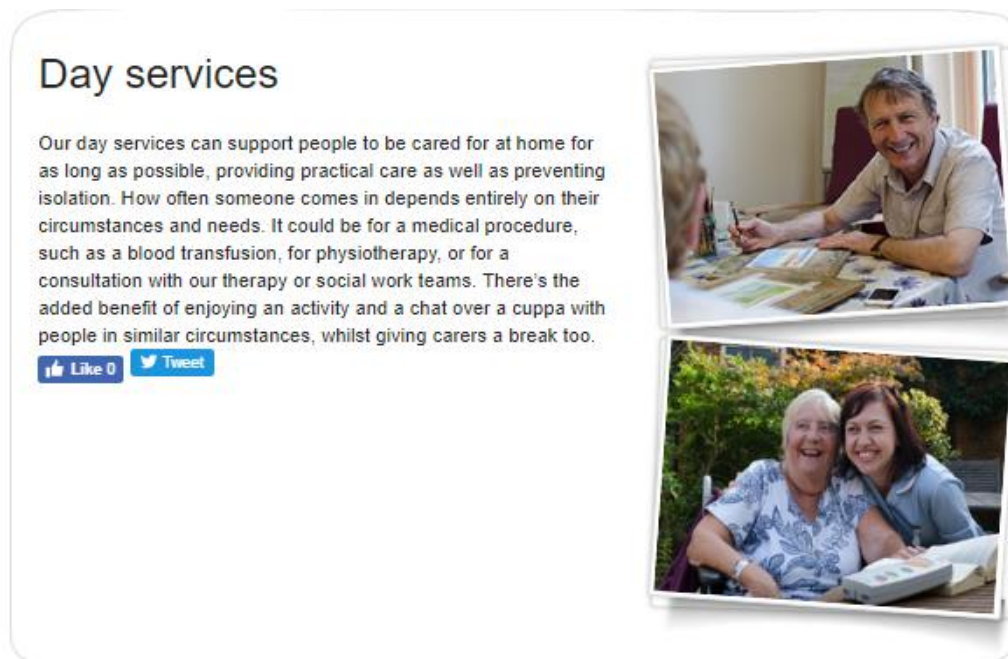
Figure 7: *A description of the day care services offered by the hospice.*

In practice, this related to how the day therapy unit aimed to cultivate an inclusive, warm, friendly, safe, and caring environment in which patients could be around others in a similar situation. As part of their "day out", the hospice offered various activities (e.g., board games, quizzes, arts and crafts, bingo etc.) which sought to bring patients together in ways that they could socialise with others. Roy aptly summarises how patients in the day therapy unit embodied this cultural value through talking about the ways in which the hospice catered for every patient's needs and how coming once a week was able to give his wife respite from the difficulties of being his carer:

> Obviously, people that come here are wanting different things, some people either live on their own and that are wanting more conversation and things like that and activities, where I've got loads of activities and I find it restful coming here, which is the different, the other side of it. I find more peaceful and I also give me wife a little break as well from me being pestering her at home … The thing about it is you can take, you can do whatever's needed, whatever you're

short of in your own life you can find a way of doing a little bit of it here.
[interview 1]

Similarly, Judy spoke about how the day therapy unit offered a unique environment in which she felt cared for and supported. Whilst there was a tacit understanding shared by patients about the severity of their illnesses, this was not something that they dwelled on. Rather, integral to their day out at the hospice was feeling as though they were able to be themselves:

AB: how about since being here at [hospice name], what's your experience of being here like?

J: Oh it's fantastic. It's just, what I like about it, apart from the fact that everyone is absolutely wonderful and so caring and so loving, is it's not about the cancer. People very rarely mention their illnesses, we just get on and have a laugh and some company and everybody just has to bolster each other up, you know. [interview 1]

To summarise, the cultural values which permeated the day therapy unit at the hospice were:

- The adoption of a patient-centred approach to improving QOL;
- Using this patient-centred approach to inform a multidisciplinary and holistic approach to patients' healthcare needs;
- Creating an inclusive environment in which patients felt safe and cared for;
- Offering various activities to occupy patients' minds and bring them together with other people who had a shared (but tacit) understanding of terminal illness. One such activity that comprised part of patients' day out at the hospice was Tai Chi.

5.3. Hospice-Based Tai Chi

As part of the services offered to day-case patients at the hospice, adapted Tai Chi sessions were delivered within the day therapy unit on the Tuesday and Thursday of each week. This meant that patients, who came to the hospice once a week (usually for a minimum of 12 weeks), had the opportunity to take part in hospice-based Tai Chi each time they visited the day therapy unit. Tai Chi sessions

were designed to fit within the holistic and multidisciplinary approach to improving patients' perceptions of quality of life through providing them with a chance to be physically active, engage in mindfulness, and take part in an activity with other patients who had a shared understanding of advanced and chronic disease.

Tai Chi sessions were lodged within the routine of the day therapy unit. They always took place within the main room of day therapy between 12.30pm-1pm, just before patients proceeded to the dining room to eat lunch. Sessions were initiated and delivered by the hospice's physio and occupational therapists, who would enter the main day therapy room and ask if patients were willing to take part. It is important to note that the offering of Tai Chi was always non-compelling; if some patients did not want to take part because they felt as though it was 'not their cup of tea', they were free to do so. Indeed, it was often the case that these patients sat quietly whilst Tai Chi sessions were ongoing, using this half an hour as an opportunity to read newspapers or fill out crosswords. For patients who were enthusiastic about participating in Tai Chi, the therapists gathered them in a small circle in which sessions were conducted.

Usually, 2 physio/occupational therapists were present during Tai Chi, with one taking the lead in guiding patients through the visual and verbal instructions that were necessary to complete movements to imagery, whereas the other took a more active role in supporting patients throughout the duration of sessions. Whilst Tai Chi was primarily conducted for the benefits of patients, it was also common for volunteers to participate. Thus, my participation during Tai Chi sessions was not seen as something unusual or out-of-the-ordinary by patients; it was something that all people were welcome to take part in.

The Tai Chi sessions themselves were adapted to suit the needs of a palliative population. This entailed a combination of gentle, seat-based bodily movements and breathing exercises that were conducted to mental imagery, mindfulness, and soothing woodwind and percussive music. For example, one routine required patients to slowly lift their arms towards the ceiling and then abduct them away from the body whilst imagining that they were a tree growing in the height of spring. Another movement entailed extending their legs and feet away from their body as they imagined dipping their feet into the cooling water of a stream on a

bright, blue summer's day. Sessions then ended with a short 5-minute relaxation routine in which patients were encouraged to sit back in their chairs, place their hands on their stomachs, close their eyes, and tune into their bodies. The physios would then take patients through various breathing practices that aimed to instil a sense of inner calm and peacefulness. For further examples of the movements and imagery that were conducted, alongside the typical structure of sessions, the guide used by the therapy team when delivering Tai Chi sessions can be found in appendix e.

5.4. Summary

In this chapter I have combined Frank's (2007) narrative template of "the drama of fear and loss" with the notion of the "temporality of illness" (Toombs, 1990) to discuss participants' lived experiences of advanced, incurable disease. Accordingly, I demonstrated how being trapped in embodied time intersected with the multiple losses and fears that participants experienced as they navigated their worlds in diseased bodies and the multiple ways in which this undermined their QOL. Furthermore, I also drew on my time immersed in the field to paint a cultural description of the day therapy unit at the hospice. Most of the descriptions included above are based on my initial impressions of the hospice environment. To date, however, I have been volunteering within the day therapy unit (every Tuesday of each week) for nearly 3 years. Within this time, my aforementioned understandings and observations of the day therapy unit culture have been continuously re-affirmed and strengthened. I am therefore confident that the cultural portrait provided above constitutes a credible account. As part of this cultural portrait, I spoke about how patients at the hospice engage in a variety of activities during their day out to the day therapy unit. One of these activities was Tai Chi. Thus, I spent the final part of this chapter describing the nature of Tai Chi sessions that were delivered at the hospice, including: the duration and content of sessions, who they were delivered by, who took part, and how many times patients had the opportunity to participate in them.

It is to how participants viewed and experienced Tai Chi within the specific cultural context of the day therapy unit that this thesis now turns.

Part 2

Empirical Findings.

Chapters 6-9 make up the second part of this thesis and include the study findings. Chapters 6-8 provide the empirical findings that are related to the first research question of this project: how did taking part in a hospice-based Tai Chi program impact participants' perceptions of their QOL? The first two chapters (6 and 7) outline the positive ways in which Tai Chi was experienced by participants through introducing the themes "the pleasures of mind-body respite" and "social engagements". Chapter 8 then introduces case studies of "outliers" to demonstrate the negative, complex, and messy ways through which Tai Chi impacted participants' perceptions of QOL. The final chapter of this section (chapter 9) focuses on answering the second research question of this project: what were patient's views on, and the barriers and facilitators that they faced in relation to, participating in Tai Chi within the socio-cultural context of a hospice day therapy unit? This comprises of 5 themes that span various levels of the social-ecological model, including: "physical limitations", "enjoyable and worthwhile activity", "group practice", "autonomy and choice", and "supervision by professionals".

Chapter 6: The Pleasures of Mind-Body Respite

6.0. Overview

As a general theme, the pleasures of mind-body respite characterised the ways in which Tai Chi presented participants with relief from the physical and mental distress that was associated with living with advanced, progressive disease. This was through how it acted as a gateway into allowing them to experience their minds and bodies in pleasurable and peaceful ways. Smith (1980, p.75) construes pleasures as emotions that pertain to "happiness, joy, fun, sensuality, amusement, mirth, tranquility". This definition encapsulates the ways through which the pleasures that participants experienced through mind-body respite allowed them to "feel good" both physically and psychologically (Phoenix & Orr, 2014, p.96). In doing so, it allowed them to learn how to re-interpret how they felt and thought about their minds and bodies.

The theme "pleasures of mind-body respite", therefore, can be understood through three, interconnected sub-themes: (a) being present in the moment; (b) embodied peace; and (c) mind-body connections. Whilst being present in the moment captures the ways in which Tai Chi assisted participants in ceasing thought and forgetting about their illness-related worries and ruminations, embodied peace represents how participants were able to experience solace from the physical distress that was an unavoidable reality of inhabiting a body that was undergoing non-negotiable, physical decline. Mind-body connections demonstrates how the mental (e.g., being present in the moment) and physical (e.g., embodied peace) benefits that were experienced through Tai Chi participation were mutual and reciprocal in that respite experienced through the mind could facilitate respite in the body and vice versa. Together, these sub-themes demonstrate the ways through which a growing sense of well-being in the mind and body acted as a doorway to the present moment and allowed participants to experience a contentment, serenity, and tranquillity of their whole being. Integral to experiences of such was participants' immersion in the gentle movements, imagery of nature, and soft music that were part of the practice of Tai Chi.

I first present these as conventional realist tales to *tell* the reader about participants' experiences of the pleasures of mind-body respite during Tai Chi at the

hospice. I then utilise a creative non-fiction to *show* the reader the same thing through (hopefully) providing a contextualised, evocative, and moving account which invites them into the lived, embodied, and sensuous worlds of a participant as she experiences the pleasures of mind-body respite in action.

6.1. Being Present in the Moment

Chapter 5.1 highlighted how participants in this study experienced a profound sense of psychological distress that occurred as a result of living with advanced, incurable disease. This was characterised by the "dramas of fear and loss" which related to worries and uncertainty surrounding the future, anxieties about progressive physical decline, and the adverse impact that their disease had on family and friends. This meant that negative thoughts and emotions were often at the forefront of participants' awareness. The mental toll of living with an advanced, incurable disease was summed up by Rachel who spoke about how the amalgamation of fears related to bodily decline and leaving loved ones behind resulted in her mind being "all over the place" [interview 1]. Tai Chi offered an avenue through which participants could experience a sense of respite from these issues, thus experience their minds in pleasant ways. This occurred through a process of re-directing their awareness away from the worries and fears that undermined their QOL and onto being present in the moment. Conversing with Jane about her experiences of such, she reflected:

> You've all got worries, but when you're doing it [Tai Chi] and you just go, they could be flying off; you forget … what gives you a problem just goes for a while. And I believe it does… not escape cos you can't escape, you know, things, but respite you know. [interview 2]

Rather than ruminate over struggles of the past or dwell on worries of the future, Tai Chi was a way in which participants could forget about their problems by re-directing (thus anchoring) their attention and awareness onto the quality of present moment-to-moment sensory and mental experiences. Accordingly, it helped them work towards experiences of mindfulness through "vipassana" (e.g., fostering an inward and non-judgemental focus on what was occurring in the here and now) (Grabovac, Lau, & Willet, 2011; Kabat-Zinn, 1982, see chapter 2.5). In these ways, Tai Chi allowed participants to change their "modes of mind" from "doing" to "being"

(Dimidijan, Kleiber, & Segal, 2010). That is, rather than dwelling on, or trying to seek solutions to their worries and anxieties, they were able to forget about them through grounding their minds in the present without evaluating or judging it with the past or future. In the words of Debbie: "I give over that half an hour to me, physically and mentally in a mindful state, I don't think of anything but doing the exercises to benefit me" [interview 2].

For some participants this was achieved through an active process in which they consciously directed their attention onto the imagery, movements, and sounds that were present during Tai Chi sessions. For example, focusing on the gentle movements and imagery of nature whilst lifting their arms up and down as they imagined themselves running their fingertips through a waterfall. Or listening to the "beautiful" and "soothing" sounds of the Buddhist music which ran throughout the duration of sessions. By doing this, participants were able to dissociate and get away from maladaptive illness-related thought processes which made them vulnerable to anxiety, worry, and depression. For example, Christie – who had been admitted to the hospice for anxiety and low mood and was feeling especially vulnerable at the time of our interview – talked about how focusing on what her body was doing, and concentrating on the background music and voices of the physios, helped her to stop thinking about her illness:

AB: What do you actually think through the sessions, if anything?

C: I don't think which sounds silly. I don't think because I'm concentrating on what I'm supposed to be doing and the music is sort of 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 calm doesn't make you think … you don't think about your condition and where you are and 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. [interview 1]

Being present in the moment provided participants with respite by helping them to cease thought of their disease and enter liminal spaces (Bruce et al., 2014; Turner, 1967) between thinking and not thinking. In this way, being present in the moment was sometimes characterised by a paradox in which participants were thinking about the movements and imagery that they were engaged in, whilst

simultaneously thinking of nothing at all. Expanding on this notion, reflecting on her experiences of mindfulness during Tai Chi, Debbie spoke about how it was like embarking on a journey in which she could get away from her illness:

> Definitely respite in that half an hour cos you don't think of anything else … that's why when it gets to the end, you've a reluctance to come back, because you've just had that half an hour of respite from everything else, just to be mindful and not think of anything, just do the movements – not even thinking about the movements, just you listen to like if it's the sea or the punching and once it's said, you just do it and somehow your minds on the movement but not focusing on the movement… It is getting away. Cos as I say, in that half an hour, I don't really, usually, I don't think of anything but listening and doing. [interview 2]

In entering these liminal spaces and ceasing thoughts of their illness and the problems that it caused them, participants could experience mental pleasures through psychological states characterised by peace, tranquillity, and contentment. A common thread that ran through being present in the moment was how it appeared to be related to participants' perceptions of time. In chapter 5.1, the importance of the temporal aspects of participants' illness with regards to their well-being and QOL were described in detail. It was often the case that because participants were trapped in embodied time (Ellingsen et al., 2012, 2013; Toombs 1990), they found it difficult to keep up with everyday life which functioned via clock time. Not feeling as though they could engage in the world, therefore, seemed to give rise to feelings of segregation and existential/emotional loneliness. However, through grounding themselves in the moment, Tai Chi represented a mindful activity in which participants could experience respite from the mental stresses and tensions associated with trying to "keep up", through transcending these time zones and entering a space of timelessness. Talking of how she used guided imagery and visualisations in Tai Chi to foster such feelings, Judy recalled:

> Well it's [Tai Chi] a calming, it calms nature. *The timelessness of it.* You can't hurry a tree, it will grow in its own time, it will die in its own time unless we poison it, of course. I think what it does, I mean I'm not so much in the hurly burly but it does take it out of the hurly burly of modern living, where

everything's rush rush rush rush rush and *it just takes you back where you've got nothing to do and all the time in the world to do it*, I think that's the feeling I get from it, yeah. "Ah Lunch is at 1 o'clock", ahh ok lunch is at 1 o'clock, ok, and I'm under the waterfall it doesn't matter that lunch is at 1 o'clock, 1 o'clock's down there somewhere, I'm here, I'm under the waterfall or picking the apples or whatever. [interview 1, emphasis added]

Being present in the moment was characterised by a cessation of illness-related thoughts, liminal spaces between thinking and not thinking, and timelessness. These experiences seemed to occur through the concoction of gentle movements, soothing music, and imagery which worked together in ways that mentally relaxed participants by helping them feel at ease and less stressed/anxious. Feelings of mental relaxation represented another form of mental pleasure that was experienced through being present in the moment and manifested itself in different ways for participants in this study. For some, the mental relaxation experienced through gaining respite helped to alleviate anxieties surrounding their disease. For example, Rachel spoke:

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 [Tai Chi] just relaxes your mind … when I'm relaxed like that, I'm not panicking, I'm not anxious … because once I start thinking, I start stressing. [interview 2]

For others, feeling mentally relaxed was a liberating and pleasant mental experience in which they could get away from a fast-paced world governed by clock time. In grounding them in the moment, mental relaxation helped participants to stop overthinking and quiet their minds from the constant stream of thoughts that was part of navigating a world whilst inhabiting a diseased body:

there's that many things going on in the world that your brain's overactive all the time, cos everything's rushed and bustling and that and I think that having the relaxation and your brain slowing down and having a bit of a breather, it benefits everybody just by being able to shut off. It's a bit like going to sleep, it's just a relaxation that everybody needs and they're not … people are that pumped up with what's gonna happen in the next 5 minutes, that they're not

getting the relaxation and I think it [Tai Chi] helps in situations like that. [Roy, interview 1]

In these ways, Tai Chi allowed participants to slow down mentally through immersing oneself in the pleasant slowness of the present moment. Speaking of the concept of slowing down, Vannini (2013, p.117) notes that it represents the ways in which we may:

affect the way in which we dwell in the world, and in turn to be affected by it. To slow down is to act and move differently, to experience the social and ecological environment in ways that run counter to the logic of speed. To decelerate is also to conceptualize livelihood differently, therefore to represent time alternatively to the logic of speed – both to oneself and to others.

Indeed, the slow nature of Tai Chi seemed to create a unique environment, which affected participants in ways that other activities within (and outside of) the hospice likely did not. This seemed to occur by allowing them to relate to their worlds in calm, pleasant, and satisfying ways. Accordingly, by facilitating sensations of mental pleasure and satisfaction, the benefits of respite experienced through being present in the moment was able to improve participants' QOL through enhancing their perceptions of subjective well-being (Diener et al., 1999). In demonstrating the importance of "being" as opposed to "doing", these findings challenge the fundamental premise on which Calman's (1984) gap theory of QOL is built. This theory proposes that improvements in QOL are achieved through the adoption of task-orientated approaches in which individuals take direct action in solving their illness-related problems. This is said to improve QOL through reducing the discrepancy between participants' present reality and their hopes and aspirations. However, chapter 5.1 demonstrated how many of participants' disease-related problems were irresolvable, for example, impending separation from friends and family through death and non-negotiable physical decline. Repeated fruitless attempts to solve these problems can culminate in pathological grief (Parkes, 2001; Stroebe & Schut, 2010) and negative loops of ruminations and worry which expose individuals to depressive mind-states that undermine their QOL (Dimidijan et al., 2010). Thus, these findings problematise Calman's notion of problem-solving to improving QOL in a palliative care context. Instead, they show the value of doing

quite the opposite. That is, improving QOL through taking time away from thinking about or attempting to solve disease-related problems and, instead, doing things that allow patients to simply appreciate the sensuality of the present moment.

6.2. Embodied Peace

According to Merleau-Ponty (1962), humans live and make sense of the world in and through their bodies. In making this argument he introduces the notion of "bodily intentionality" which emphasises how the body "is always [conscious] of something; it is thus intentional, directed or orientated towards something or someone" (Allen-Collinson, 2009, p.287). As discussed in chapter 5.1, functioning within the embodied rhythms of inner time seemed to be an all-consuming experience in which deeply unpleasant physical sensations (e.g., muscle tightness, body tremors, swelling, nausea, and pain) "trapped" participants and made time feel slow and arduous (Buetow, 2004; Ellingsen, Roxberg, Kristoffersen, Rosland, & Alvsvag, 2015; Gergel, 2013). In doing so, embodied suffering occupied the centre of their "bodily intentionality" (Merleau-Ponty, 1962) in perpetual and uncompromising ways. Participating in Tai Chi, however, helped to soothe participants' bodies, through re-directing their bodily intentions away from fleshy, corporeal traumas and onto experiencing their bodies in pleasurable ways.

Phoenix and Orr (2014) provide an account of the different types of pleasure (e.g., sensual, habitual, documented, and immersive) that may be experienced through engaging in physical activity. In this study, participants' experiences of embodied peace were represented by a combination of sensual (e.g., through the senses) and immersive (e.g., an appreciation of their bodies in the present moment) pleasures that were associated with taking part in Tai Chi. Experiences of sensual and immersive pleasures were intertwined. This was through the ways that participants were able to appreciate their bodies in the present moment through immersing themselves in the various sensual pleasures that engaging in Tai Chi provided.

In regard to sensory pleasures, participants often referred to how the *sound* of the beautiful music, the *touch* of the cold water as they visualised being under a waterfall, the *kinaesthetic* beauty of the gentle and soft movements, were able to instil a sense of physical calm and inner peacefulness. Immersing oneself in these

sensory pleasures were discussed by participants as being transformative experiences in which they could temporarily escape from the visceral discomfort of their disease. One such sensory pleasure that was an integral part of embodied peace was that of physical relaxation. This was a state of physical calm which represented the way through which engaging in a series of gentle movements done to music and imagery reduced physical tensions, thus enabled participants to feel at ease, within their bodies. Speaking of her experiences of physical relaxation, Debbie reflected on how the kinaesthetic feel of her muscles gently moving during Tai Chi was able to reduce tensions and instil a sense of physical relaxation that extended beyond Tai Chi sessions and into other activities that she later participated in at the hospice:

> 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, you know, like a contraction and when you relax it, 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. [interview 2]

For some participants the lasting effects of physical relaxation was even more profound. In an interview with Janine, she spoke about how it lasted beyond her day's stay at the hospice:

> AB: Would you say that the benefits that you get through the relaxing part of Tai Chi at [hospice name] extends beyond the sessions?

> J: Oh yeah. Ooh I feel, I can't explain, when I've been here, I feel as different again when I go home, it's lovely. [interview 1]

Feeling physically relaxed was an integral aspect of Tai Chi which provided participants with a much-welcomed sense of embodied peace and relief from the disease-related physical distress that pervaded their everyday lives. Another sensory

pleasure that was experienced as part of embodied peace was rest. Experiences of restfulness manifested through Tai Chi via feelings of a pleasant tiredness and was particularly important for participants who struggled with sleep. The soft music and visualisations of nature that were part of the Tai Chi sessions presented an opportunity for them to rest and recuperate their bodies in ways that they seldom found possible within their own homes. For example, Stan recalled:

> I like a few different parts of it [Tai Chi]. 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. [interview 1]

Similarly, Janine spoke about how the pleasant tiredness and restfulness that she experienced during Tai Chi gave her a peaceful high:

> AB: What physical benefits have you had through doing the Tai Chi?

> J: Ooh 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. [interview 2]

Whilst for some participants restfulness was experienced in the sense of feeling pleasantly tired, for other participants, it was about alleviating the unpleasant corporeal effects (e.g., muscle tightness, body tremors, swelling, and nausea) of their disease. In this way, Tai Chi was able to disrupt the vicious and exhausting circle of discomfort associated with the physical symptoms of their illness and side-effects of treatments. For example, Christie spoke about how as a result of her disease she experienced persistent and fatiguing leg shaking which dominated her life. Tai Chi was a method of respite from this, thus a way for her to experience the physical presence of her body in restful and pleasant ways:

> I shake so much that in the Tai Chi sessions it usually helps me stop shaking which means I don't use as much energy, so I don't get as tired.… it's so tiring

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is the shaking…it's [Tai Chi] nice and slow and your body gets a rest, you do your legs and then you stop and do your arms, so your body parts get a rest. [interview 2]

Observations of participants' postures (e.g., slouched shoulders, relaxed limbs, and deep and calm breathing) and facial expressions (e.g., closed eyes and relaxed facial muscles) made evident how experiences of restfulness and relaxation complimented each other. For example:

At the end of the session patients were instructed by the physio to lean back in their chair, close their eyes and focus inwardly on their breathing and releasing the tension from all of their muscles, working from the head all the way down to the toes. The calming and peaceful melodies of an array of string and woodwind instruments pervaded the room amongst periodic "poofs" of Rachel's oxygen machine. Whilst I was sat in the circle engaging in this final part of the session I sneakily opened my eyes and looked around the room to observe participants' responses. They were all consumed in the back of their chairs, loose-limbed, with their eyes closed and breathing calm and deeply. Soon after the session had finished Leanne turned to Jane and told her "ooh I almost fell asleep there." To which Jane smiled and agreed. [observational field note]

The amalgamation of physical relaxation and restfulness that was conjured through engaging in the gentle movements, imagery, and music of Tai Chi resulted in another form of embodied peace: revitalisation. Words like "cleansing", "re-energised", "reinvigorated", and "rejuvenated" were used to convey how the restful and relaxing nature of Tai Chi fostered feelings of physical restoration and renewal. Through doing so, Tai Chi was a way for participants to feel physically better and brighter in themselves. This was evident in Debbie's reflections of the paradoxical experience of feeling tired yet re-energised after Tai Chi:

D: [during Tai Chi] I like to close my eyes and just re-energise my whole body and it's an energy that leaves you feeling tired at the end, but I think it's because it's not hard work … that half an hour is just so re-energising.

AB: it seems like there's almost some sort of paradox in that you're tired at the end but re-energised. Is that how you experience it?

D: It is because you're relaxed and you feel like "wow" but at the same time you just feel great [smiles]. You know I can't describe it, you know, like we all go "ooh I could just go to sleep", which you could but also its lovely that you just feel "wow", what you've just done, you know … I feel relaxed yet rejuvenated at the end of it. [interview 1]

Experiencing states of embodied peace through relaxation, restfulness, and/or re-vitalisation seemed to act as a form of embodied knowledge that allowed participants to relate to their bodies in different ways. Embodied knowledge refers to the hard-to-define and pre-reflective "bodily foundations of knowledge" (Ignatow, 2007, p.115) that is learned through direct sensory and perceptual experiences and subsequently stored within the tissues of the visceral body. Indeed, whilst many participants recognised embodied peace as an integral aspect of Tai Chi sessions, many found it difficult to put their experiences into words; it was an intuitive and experiential phenomenon which could only be understood through doing Tai Chi. For example, the following interview extract demonstrates how Janine struggled to verbalise what she meant by embodied peace, yet still recognised it as something that was integral to her Tai Chi experience:

It's so hard to explain. Erm, peace. Peace is the word. Peace … it's so difficult to explain but it does, cos when you're sat there and doing, you're trying to imagine what they lady's saying and then it's, it's so hard to explain. But it's for me, definitely. [interview 1]

Through experiencing their bodies in gratifying ways, participants were able to ameliorate their QOL through enhancing perceptions of their subjective well-being. That is, Tai Chi was a means of maximising embodied pleasures and minimising embodied pain, fatigue, and other negative bodily sensations that riddled their everyday lives (Diener et al., 1999; Ryan & Deci, 2001). In doing so, Tai Chi appeared to foster a new awareness of the body (Hefferon, Grealy, & Mutrie's, 2009). This is a type of post-traumatic growth (Tedeschi & Calhoun, 1995; 2004) which captures how during physically traumatic situations such as terminal illness, patients may seek to re-connect with their body through figuring out ways in which they can positively identify with it. Indeed, these data suggest that the experiences of

embodied peace that were fostered through taking part in Tai Chi allowed participants to identity with their bodies in positive and pleasurable ways.

The ways in which participants' lived and embodied experiences of subjective well-being were located, negotiated, and socialised within the specific cultural context of the hospice (as described above) can be further illuminated by Andrews et al's (2014) notion of "affective environments". Guided by a "relational ontology" to well-being, the concept of affective environments suggests that because bodies are open to and influenced by their interactions with other human and non-human objects within their surroundings, lived experiences of affect (i.e., well-being) are also a *part of* the environments in which they occur. Indeed, various non-human objects present within the affective environment of Tai Chi provided a multitude of sensory cues (e.g., sounds of music, soothing ambiences, and visualisations of nature) that were integral to experiences of embodied peace. These features of the environment were embodied by participants in the ways that they seemed to be transmitted into their bodies and experienced at pre-reflective levels that were characterised by soothing physical sensations (Andrews et al., 2014). In these ways, the space and place in which Tai Chi was conducted (i.e., the hospice's day therapy unit) appeared to act on participants in and through their senses, thus fostering states of "positive affection"; types of "joy affect" that were able to re-energise and reinvigorate them (Andrews et al., 2014). For example, Janine alluded to the importance of the day therapy as an affective environment through commenting on the importance of the atmosphere (e.g., dimmed lights and quietness) in which Tai Chi was conducted:

> 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, they were, 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. [interview 2]

Another important feature of the affective environment of Tai Chi were the embodied ways in which participants interacted with other patients that were present in sessions. Because during Tai Chi sessions participants' bodies recursively and reciprocally affected, and were affected by, each other (Andrews et al., 2014)

experiences of subjective well-being that were generated through embodied peace can be described as "intercorporeal" (Allen-Collinson, 2016). That is, the mutual embodied connections that were shared whilst doing Tai Chi acted as another source of positive affection through spreading feelings of well-being from one participant to another (Andrews et al., 2014). For example, Rachel spoke about how feelings of physical calm were accentuated by seeing other people looking relaxed and rested:

AB: The shape is always a circle isn't it? Do you feel that's important at all?

R: Well, yeah because … [you] can see other people and they're all doing the same thing and it's calming to see that other people look calm as well, you know. [interview 2]

The ways in which participants' bodies interacted with each other in mutually facilitative ways within this affective environment resonates with Conveney and Bunton's (2003, p.168) assertion that carnal pleasures "connect the body to the world. They literally 'open up' the body to the influence of other people and the wider environment. The notion of a body open to senses indicates a sharing of values, rituals and community". In opening themselves to the world, the assemblages of participants' bodies and objects within the physical environment (e.g., chairs, music, and lights) gave way to a variety of "affective possibilities" that were unique to the activity of Tai Chi. Affective possibilities refer to how "certain places attain reputations for providing opportunities for particular types of affective feeling states. Because of this identity, they might become focal points for individuals who value them and seek them out" (Andrews et al., 2014, p.218).

Indeed, there were unique routines and "tacit rules" (Spradley, 1980; Wall, 2015) at the hospice, which moulded and mediated the ways in which Tai Chi developed a reputation for becoming a time in the day in which embodied peace could be experienced. These routines did not seem to be present in other activities such as arts and crafts, quizzes, and board games. Tai Chi was unique in that it included the dimming of lights to create a soothing ambience, explicit efforts to be quiet and not create loud noises (e.g., loud talk or slamming of doors), and soft music taking a central role in the room's soundscape. In this way, Tai Chi can be viewed as its own unique sub-cultural activity within the broader cultural context of

the hospice. An informal conversation I had with two participants (Debbie and Karen) exemplifies the reputation that was ascribed to Tai Chi within the hospice:

> Before Tai Chi had started I was sat around a table at the side of the circle of chairs that occupy the centre of the day therapy unit room. Sat with me was Karen and Debbie who, like me, were getting in all sorts of mess making papier mache face mask. With half 12 fast approaching Karen brought up the topic of Tai Chi in our conversation saying how "it'll be time to do Tai Chi before you know it." Debbie, looking up from her paintbrush smiled and responded to this saying: "ahh, good. It's one of my favourite things that we do here."

In an attempt to understand what Tai Chi meant to them within the context of their day's stay at the day therapy unit at the hospice I probed further by asking what specifically they liked about it. Debbie then responded:

"It's a time in the day in which we can relax ourselves, I always feel right tired after we do it. It's a relaxing tired … a good tired". It was at this point Karen nodded, smiled, and agreed. [informal conversation emphasis added]

Accordingly, participants seemed to take what Heidegger labelled as "pre-understandings" or "projected meanings" into sessions which, in part, impacted how they experienced embodied peace (Dallmayr, 2009). These refer to the ways in which participants did not enter Tai Chi sessions as blank slates, rather, they went into them with certain expectations and understandings of how it offered an opportunity for them to experience their bodies in pleasurable ways (Dallmayr, 2009). As shown in the quote above, these projected meanings were negotiated within the cultural context of the hospice. What embodied peace meant to participants, therefore, was shaped just as much by the socio-cultural and inter-embodied/subjective processes that occurred within the context of the day therapy unit as it was a result of their physical experiences during Tai Chi. Consequently, embodied peace (and the pleasures of mind-body respite more generally) was not something that was experienced automatically through taking part in Tai Chi but was heavily influenced by the ways through which it became moulded as such an experience within the cultural milieu of the day therapy unit.

Critical reflection 7: Thinking with and through the body/senses

Most of my initial observational data was ocular-centric in that it focused on what I observed through vision alone. An extract from my reflexive journal recognised this:

> "Over the last month or so, I started to realise how a lot of my observations were comprised of the same (or similar) events/actions *of what I have seen*. This has got me thinking, is there a whole other world of information that I am missing through neglecting the other senses?"

This left me with a distinct feeling of not really "getting" what participants' embodied experiences of Tai Chi were like. Inspired by the works of various scholars (e.g., Culver et al., 2012; Kumate & Falcous, 2017 Smith et al., 2016; Sparkes, 2016a, 2016b; Turner, 2000), therefore, I sought to immerse myself in the sensuousness of Tai Chi sessions through adopting the role of a "complete observer" (e.g., fully participating in all aspects of Tai Chi without collecting field notes). I felt that this was a way in which I could enrich my understanding of participants' experiences through becoming a "sensuous apprentice" (Sparkes, 2016a, p. 345). That is, using my own embodied experiences of Tai Chi to develop an "experiential knowledge" (Allen-Collinson, 2015, p.18) of what it was like for participants to take part. Indeed, it did. Through immersing myself in sessions, focusing on how the music sounded and the kinaesthetic and proprioceptive feel of movements, I felt a sense of peace pervade my entire body; I started to *really* understand what participants meant when they said they felt a pleasant tiredness, physical relaxation, and revitalisation. I was particularly struck by how pleasurable this all felt. These experiences helped to enrich my understandings of data collected from other observations and interviews. Thus, rather than representing participants' experiences in separate themes entitled "physical relaxation" and "revitalisation" (as I did in early analysis of the data) I was able to capture the visceral and sensual aspects of Tai Chi that were so important to participants' experiences of QOL. This thought process led to the notion of "embodied peace" as presented in this sub-theme.

6.3. Mind-Body Connections

Whilst participants' experiences of mental (e.g., being present in the moment) and physical (e.g., embodied peace) respite have been described separately above, it is important that the mind and body are not sequestered when coming to understand participants' experiences of Tai Chi and how this impacted their perceptions of QOL. The pleasures experienced through respite in the mind recursively interacted with the pleasures experienced in the body in mutually facilitative and reciprocal ways. Therefore, this next section highlights the explicit ways in which the two were connected during Tai Chi practice.

Participants' experiences of mind-body connections during Tai Chi was commensurable with the Chinese notion of "Yi". This represents the "meditative intent" that underpins Tai Chi practice and is said to enhance and enrich the quality of our lives through the accumulation, circulation, and storage of vital energies (Qi) throughout the body (Klein, 2017). This is said to occur through using a combination of gentle body movements, breathing, and mindfulness to connect the mind with the body in ways that can facilitate the flow of "positive" energy into, and discharge "negative" energy out of, the body (Klein, 2017; La Fonde, 2005). Indeed, Jane's account of how Tai Chi was able to relax her mind and body in interconnected and reciprocal ways demonstrated Yi in action:

> The mind and body work together in it, you know, you're doing your movements which are very relaxing movements without doubt, and as you're relaxing, your mind starts to relax, you stop thinking about things. You're more, you're listening to the music and you're not thinking about other things and with the music your arm movements come, it's a combination … [doing Tai Chi is] more a case of just drifting away, as if erm, shut is the wrong expression, cos that's too fast, as if there's just something coming down which just lowers, or goes up, which spreads the relaxation... you don't switch off from listening, hearing things, but when you relax and completely relax, the feeling of body relaxing and mental, you can feel it, you know, you sit there and you feel that energy, erm, wrong energy. What I'm trying to say, the energy that keeps you bustling around, that goes out of you and your whole body and your mind, and you just sort of come to peace. [interview 2]

Experiencing the physical and mental aspects of Tai Chi in mutually facilitative ways provided participants with benefits that perhaps would not have been fostered had they taken part in exercises which focused on just moving the body alone:

AB: You spoke about kind of the movement and the exercise and also the mind aspects, almost the mind-body connection [B: yes]. Do you feel that in the sessions? And how do you feel it? I know they've got the visualisation aspects, how do you feel when you're doing that?

R: Yeah, I think it's very important that you get both at the same time. Cos, like I was saying, what I need as much as 'owt is relaxation because things I do are all very tense, so felt relaxation is very helpful to me and doing it with physical relaxation, with exercises at the same time as mental relaxation is like double. So, yes, you can't fault it for that. [Roy, interview 1]

Similarly, the uniqueness of Tai Chi as a holistic therapy which combined visualisations, gentle movements, and music was noticed by Debbie who highlighted how it was different to others forms of exercises and physical activities:

Oh, well I'm very good at visions, you know so when she says waterfall, I'm there with the waterfall, I can see it, I can feel it even sometimes, especially at the end when you're scooping the water and let it trickle down your face, I think you just have to visualise it and it's there, well, it is for me … It just seems to fit together somehow, you know, the movement that you do in Tai Chi fits so well with the imagery. *Whereas in an ordinary exercise class, you don't get that, you know, it's all physical patterns that you're doing in an exercise class, whereas with Tai Chi, it's a whole experience I think.* And I think the imagery of Tai Chi is relevant to relaxation in like the sea, the waves on the sand, water tricking, you know, all that kind of stuff, the images, the names of the physical activity are relevant to the activity. [interview 2, emphasis added]

Implicit throughout the theme of the pleasures of mind-body respite is how taking part in Tai Chi provided the opportunity for participants to learn how to think about and relate to their minds and bodies differently. Griffin (2017) provides a unique perspective on embodied learning which may provide a fruitful way of understanding how Tai Chi allowed participants to re-interpret how they thought and

felt about their minds and bodies. Her conceptualisation draws on the work of Merleu-Ponty (1962), Crossley (1995, 2004) and Shilling (2017) to demonstrate how learning occurs at the intersection of an individual's practical, sensory, and cognitive experiences. From this perspective, embodied learning is understood as a combination of an individual's pre-reflective, sensory experiences and their subsequent cognitive reflections on these. Accordingly, Griffin recognises the intimate connection between the mind and body during embodied learning and, in doing so, perfectly captures what the pleasures of mind-body respite seemed to mean for participants in this study. That is, through fostering a sense of embodied peace and being present in the moment, taking part in Tai Chi allowed participants to (re)learn how to live in and through their minds and bodies in different (more pleasurable) ways. This synchronicity between the mind and body suggests that two separate, yet inter-related and mutually facilitative, routes of learning took place through taking part in Tai Chi. These can be understood as "noetic" (e.g., knowledge held in the mind) and "anoetic" (e.g. sensory understandings held in the body) (Shilling, 2017). Thus, instead of allowing themselves to become consumed by "the dramas of fear and loss" and the fleshy traumas of their illness (as demonstrated at length in chapter 5.1), the soothing and pleasurable mental and physical effects that Tai Chi had on participants assisted them in reframing their understandings of their bodies and minds as potential (or at least temporary) sources/sites of pleasure and peace.

6.4. Creative Non-Fiction: "Debbie's Tai Chi Journey: Getting Away"

Eleven and a half thousand miles away from home, Debbie is sat with her 3-year-old grand-daughter in her son's living room in New Zealand. His wife was set to undergo an operation for spinal compression and Debbie was there for moral support. "That doesn't feel right" she thinks. That *really* doesn't feel right. Heart pounding, skin perspiring: "why aren't my toes moving?" she panics as she feels an alien sensation mercilessly creep its way up her body like a high striker. "Why can't I move my legs? Why can't I feel my body? Please don't go any further," she pleads. Debbie takes a deep breath and steadies herself as she reaches her perspired hands onto the table, grabs the phone, and calls her son: "John, can you get someone to come round to the house, I can't move."

"What d'you mean you can't move? What the fucking hell d'you mean?" he shouts.

"I don't know what it is, I just sat down and now I can't move," she replied.

'Stay there, I'm ringing an ambulance and coming back,' he assures her.

After a 50-minute ambulance journey, Debbie finds herself catheterised as she lies flat on her back and is entered into the narrow tube of the MRI scanner.

"Is it an aortic aneurysm?" she questions the nurse with nervous expectation.

"No, love," she replies turning her head and placing her hand on Debbie's shoulder, "it's worse than that – you've got a spinal tumour."

6 weeks later

Painstaking test after painstaking test, Debbie finally learned the cause of the foreign invader in her body. The spinal tumour was a result of metastatic breast cancer that had spread, housed itself in, and ruthlessly severed her spinal cord. Before retiring, for 12 years Debbie was a senior spinal injuries nurse and was well versed in the acute symptoms and difficulties that patients experienced whilst on the ward. But she was much less attuned to the suffering that occurred behind closed doors. There was no escaping these now for it was they which had become her reality.

"Ouch!" struggling to breathe, Debbie's face grimaces and her teeth clench as her nerves treat her to the first of her daily dose of excruciating root pain. All up her torso and legs throbbed as a stabbing sensation ruthlessly raged itself up and down her body. Whilst in reality this only lasted a few seconds, it felt like a lifetime. "Please don't jerk" she politely asks her arm as she carefully guides her mug towards her mouth and glugs her first sip of tea to help wash down her tablet. "Thank god for these," she mutters to herself. Without them, Debbie can't begin to imagine the pain she would be in. From her nursing days, Debbie knew about root pain; she knew it was when people's nerves went bananas because they don't know where to go anymore, but she didn't realise quite how painful it could be. In the midst of her morning struggle, Becky [her daughter] gently enters the room and smiles:

"Morning, Mom. Are you ready to get up?"

Debbie's shoulders drop as she peers over to her and sighs "yes, ok."

Becky rolls her this way and that, forwards and backwards, side to side, navigating around the bed's side as she places her limp and heavy leg into her trousers and pulls them up to her waist. Debbie momentarily closes her eyes, takes a deep breath and purses her lips. She re-opens them to meet her daughter's gaze:

"I'm sorry, Becky."

"What for?" she asks.

"You shouldn't have to do this. You're always the one here first thing in the morning and last thing at night helping me to brush my teeth, take my tablets, get me ready. I've lost the feeling and the use of me body, but you have lost your Mom in a way and I've lost being me. I used to support you and now I can't even stand up to hug you anymore."

Now sat in her wheelchair Debbie peers down at her torso and legs. "This isn't me" she thinks. "I'd never have come out with trousers on like this and black socks and a pair of crocs. It's just not me but now it's the disabled me. Ah well, it doesn't matter cos I'm disabled, people expect it, people will just let it go." Debbie starts to ruminate of life before New Zealand. Of how she used to do these mundane things for herself. Of how she used to take her little dog for walks. Of how she went to ballet twice a week. She had always planned to go to Ireland and back to New Zealand.

She had been looking forward to her grand-sons first communion next year and watching the tennis at Wimbledon. These things were now out of reach. Like the tears that can often haze her vision, life had become blurred. Never mind she thinks with a smile:

"It's Tuesday, less of the negative thoughts, it's time to get away from them," and with that she propelled her wheelchair outside, into the car, and off to the hospice.

Later at the hospice

It's almost half 12 already; it never surprises Debbie how fast time seems to go whilst at the hospice. Debbie see's the physio enter the room and knows that this means Tai Chi is imminent. With that she adds the finishing touches to her papier mache masterpiece that she had been working on all morning and feels the cyclical motion of metal wheels glide across her fingertips as she rolls her wheelchair into the centre of the room where a circle of chairs is formed. This journey is effortless; it is almost as though the circle possesses calming whirlwind-like properties which gently sucks her into a peaceful lacuna far away from the outside world and everything that it entails. Willingly surrendering herself in becoming consumed, she could just about make out the sweeping guitar picking of The Animals playing out of the speakers over the laughter of two other patients. "There is a house in New Orleans, they call the ri…" As she positions her chair and clinks in the breaks she notices the music abruptly stop and the ambience of the room start to change. Glancing over, she can see the physiotherapist sliding another CD into the lips of the CD player. "Click" "click" "click". The bright white lights that have illuminated the main room of day therapy since she got here this morning turn off. Now only natural sunlight glistens into the room as it shines through the trees in the hospice gardens. People have stopped talking as they ready themselves in their chairs. Slowly but surely the music elevates in volume. An eclectic mix of Buddhist chants combined with woodwind, string, and percussion instruments creates a soothing melody that gently pervades the room and floats its way through the canals of Debbie's ears and lodges itself deep into her soul. 'Shhhhh, ump, shhhh … tssshhhhhhhhh", the sound of Rachel's oxygen machine creates a swishy sound that adds to the room's new, restful soundscape. An atmosphere of tranquil harmony fills the room.

Just as Tai Chi begins, a nurse who has just finished her lunch break walks into the main room and needs to get back into the nurse's office at the other side. She tentatively tip-toes across the room whilst signalling a "sorry" to the physio's and opens and closes the door gently, ensuring it doesn't bang, click, or make any other sound that may interrupt the gentleness of the Tai Chi session. Sat at the apex of the circle, the physio begins to instruct patients:

"now imagine that you are in front of a waterfall. As you extend your arms forward and lift them up to the bright blue sky, imagine the cooling water trickling over your fingertips."

For Debbie, this was the start of a journey. It was like switching on a car engine and cruising off into the distance, away from all of her life's troubles and problems. Breathing deep and steadily, Debbie's eyes were lightly closed and she became entrapped in a deep trance as she calmly lifted her hands from her waist up towards the ceiling. In her mind, she is well and truly at the first destination; her whole essence is devoured by it. "Pit pat pit pat pit pat", the glimmering sheet of blue water fell down the side of the ragged mountain face as it gushed downwards and pounded onto the rock faces below. The drizzling water residue floats its way onto the back of her neck giving her goose bumps as she breathes in the sweet fragrances of fresh mountain air deep into her lungs. She imagines gently lifting her hand into the waterfall and allowing the running water to travel through and caress her fingertips like a blue satin cloth, cooling her ever-warm hands as it tingles itself through her body. Lifting her hands up and down the waterfall one last time, it is as though Debbie can feel every last muscle fibre in her body pushing and pulling as they tense and relax, enveloping and cleansing her body in a blissful sheath of peacefulness. This was a place that she had come to appreciate since arriving at the hospice. Boarding on this journey was the perfect remedy for the tensions and pains that often plagued her life. Her body felt remarkably different to how it did this morning; full of vigor and vitality.

Carrying on with the waterfall movement, Debbie opened her eyes and focused intently on her hand as she lowered it across her face for the third time. Lowering her brows and scrunching her nose, Debbie's face changed as she noticed how they looked all wrinkly and pale. "Ugh these looks horrible. All shaky,

discoloured, and weak," she thought to herself. Whilst this diversion of thought lasted only a millisecond it was long enough to make her feel uncomfortable within her own body.

Putting this thought aside, Debbie continues the journey Tai Chi has allowed her to embark upon. "How is it that part of the session already?" she thinks to herself as the physio guides patients through the final relaxation technique:

"now take time to sit back in your chair and place your hands on your stomach. Shut your eyes and relax every part of your body. Unclench your teeth and relax your cheek muscles. Allow your head to lay back on the headrest on the chair. Release the tension from your shoulders so that they fall into the back of the chair."

Debbie takes her up on this offer and slumps her body against the back of her wheelchair almost as though she has melted into it. Her eyes shut and face droops as she breathes deep and heavily. As she focuses on the warmth of her hand radiating her stomach she relishes in the physically and mentally mindful states that this journey has allowed. Life can be quite stressful and at times gets her down but as she basks in the soothing sensations of her body, she notices that for this half an hour journey, she has been pacified from her feelings of guilt, disappointment of lost hopes and dreams, and fears of the future. They have faded into the distance; niggly things which so often cause her problems in her everyday life seem to have drifted away. It has been just her, utterly caught up in the wonders of imagery and sensations of imagining herself moving through the natural world. Sure, these problems will no doubt return, but for now, they are gone. It is just her and the Tai Chi. Despite her negative moment, Debbie felt fulfilled during Tai Chi and takes time to appreciate and treasure these brief moments away from everything as though it was the last thing she did. Mid-thought, the voice of the physio elevates softly above the music:

"Now start to open your eyes and slowly come back round into the room," she tells them.

"I don't want to, its lovely where I am thank you very much." Debbie says to herself as she reluctantly opens her drowsy eyes and ends the voyage on which Tai Chi has taken her. She knows that it is time to come back to reality.

As she stretches her arms above her head and yawns, Debbie turns and smiles to Georgia who is sat at the side of her and asks:

"How'd you find it, Georgia?"

Returning a weary-eyed smile she calmly replies: "Great. If only I could pull up a bed now and lie down I'd be away with the fairies."

"Me too." Debbie jokes back.

And with that, the music stops, lights flicker on, and rumbles of conversation start vibrating around the room. "Time for lunch!" shouts the activities co-ordinator in his always-cheery voice. Un-clicking the breaks of her wheelchair, Debbie proceeds into the dining room where her shepherd's pie awaits.

6.5. Summary

In this chapter I described the theme of the pleasures of mind-body respite to demonstrate the impact that Tai Chi had on participants' lived experiences of QOL through the ways that it provided them the opportunity to *get away* from the physical and psychosocial distress that their illness caused them. Specifically, I initially utilised conventional realist tales to *tell* the reader how Tai Chi was a way for participants to dis-identify from distressing disease-related thoughts through anchoring their awareness in the present moment. Furthermore, I also showed how taking part in sessions was a way for participants to experience a sense of embodied peace through experiencing their bodies in physically pleasant and soothing ways at a time in their lives where they were in perpetual physical discomfort. Experiences of mental and physical respite were inextricably interconnected and reciprocal in that mental respite (e.g., being present in the moment) facilitated physical respite (e.g., embodied peace) and vice versa. Weaved throughout these realist tales were the ways in which lived experiences of mind-body respite were located within the social context of the hospice. Because of the affective environment that it created, Tai Chi represented a unique sub-cultural activity within the broader cultural context of the hospice. I further supplemented these realist tales with a creative non-fiction in order to *show* the reader the situated, embodied, and sensuous experiences that were integral to participants' experiences of the pleasures related to mind-body respite. In the next chapter, I continue to show how taking part in Tai Chi sessions within the

day therapy unit at the hospice was able to enhance participants' perceptions of their well-being and QOL through exploring the theme of *social engagements.*

Chapter 7: Social Engagements

7.0. Overview

This chapter adds to the previous through further answering the research question pertaining to how taking part in a hospice-based Tai Chi program influenced participants' perceptions of their QOL. A multitude of psychological theories and concepts emphasise the importance of fostering connections and forming mutually caring bonds with others in order to improve QOL. Through presenting the theme of "social engagements", this chapter draws on some of these theories to demonstrate how the socio-cultural environment in which Tai Chi was conducted was integral to participants' experiences of QOL. It does so through two, closely related sub-themes: (a) meaningful social connections; and (b) mutual empathy and reciprocal support. In presenting these findings, this chapter adds novel insight into our understanding of how Tai Chi may positively impact perceptions of social well-being in this population. Specifically, it does so through highlighting the importance of the hospice as a unique cultural context in which participants could participate in Tai Chi and work together to cope with the trauma of their illness.

Critical reflection 8: The importance of the socio-cultural environment

Quite early on in the field I recognised the importance of the social environment that Tai Chi was conducted in. As a snippet from my reflexive journal shows:

> "the cultural environment in which Tai Chi is conducted has quickly become an obvious factor which contributes to participants' positive experiences. Many participants have spoken about the pleasantness of interactions they share with other patients and how it provides an opportunity to do something with other people. In fact, I have experienced this myself through actively taking part in sessions."

These were initially presented as "analytical hunches" (Parkinson et al., 2016) labelled as "alleviates isolation", "belonging", "comfort", "safety", and "inclusivity". Through prolonged engagement and using the technique of "thinking with theory", I was able to enrich my understanding of these initial ideas to form the sub-themes that are now presented.

7.1. Meaningful Social Connections

Within the day therapy unit at the hospice, Tai Chi represented an activity which helped to break down barriers (e.g., being sat in different areas of the room, engaging in different activities, and sitting in specific groups of friends) between participants, through creating an environment which brought them together under a common goal and shared activity. For example, it would often be the case that some participants would be engaged in card or board games (usually between 3-6 people) in one area of the day therapy unit, whilst at the same time another group would be engaged in something else (e.g., arts and crafts, or sitting around talking). This meant that participants would often be fragmented around the main room of the day therapy unit. Tai Chi, however, was an activity which explicitly brought everyone together and bounded participants spatially. In describing their experiences of being with others during Tai Chi, participants often used words and phrases such as "togetherness", "oneness", "inclusivity", "belonging", and "like a family". This sense of unity provided a way for participants to enjoy spending time with other patients who they would not usually interact with at the hospice. For example, reflecting on how Tai Chi was an activity that brought together patients from all walks of life Jane spoke:

> Were all entirely different. We're all from different backgrounds, different job situations, whatever, we're married or single, whichever we've done. I think when you're in that group doing it [Tai Chi], that's nice, because it brings you as a unit together, where you may not, 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. [interview 1]

The experience of "doing" Tai Chi together united participants and represented its uniqueness as an activity which fostered a sense of belongingness and comradeship within the larger cultural context of the hospice. This is because the social environment that Tai Chi created represented its own sub-cultural activity in which participants were located and socially interacted in different ways compared to other activities undertaken at the hospice (Spradley, 1980; Wolcott, 2008). What made Tai Chi distinct from other popular activities (e.g., arts and crafts, therapies, dominoes, and card games) is that the combination of choreographed movements,

music, and imagery allowed participants to move their whole bodies and minds in unison. This synchronisation and co-ordination represents what Sebanz, Bekkering, and Knoblich (2006) call "joint action". That is, in the coming together of their minds and bodies, participants transcended boundaries of the self and worked together as synergies towards the common goal of feeling better.

In attuning their movements and minds with one another, participants seemed to construct a unique "therapeutic landscape" (Gesler, 1992) in which they embodied a "moving sociability" (Doughty, 2013, p.141). This refers to the ways in which bodily movements were able 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). Accordingly, participants' intersubjective and embodied interactions were anchored in a shared, cultural space which enabled their bodies to interact and "bounce off" one another in healing and therapeutic ways that were conducive to improving their QOL (Doughty, 2013). These communications were often non-verbal and represented the ways in which participants inhabited "communicative bodies" where they were able to interact with each other through the ebbs and flows of movement and body language (Doughty, 2013). Demonstrating the importance these intersubjective interactions, Judy recounted how the group working together in a circle was a healing experience:

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

Similarly, in an interview with Roy, he spoke about the benefits to his social well-being that he experienced through the ways that synchronised embodied interactions (e.g., all performing the same movement to the same piece of imagery) allowed participants to meaningfully connect with, and "feed off", each other:

> R: it's done as like a group, group therapy and because it's done as a group, you also feed off each other with your energies and your relaxation, and calmness, and it helps go from one person to another if you're in an environment where everybody is thinking on the same lines

AB: And have you felt that then?

R: Yeah

AB: So as an example, what would it be like, how have you felt that before?

R: By having people who's all on the same wavelength, all wanting to achieve the same thing and by sort of bouncing it off each other, that you're all happy in the situation where you're helping each other and them helping you as well, so it's like a win-win situation. You're giving and they're giving back. [interview 1]

Central to joint actions and the forming of such therapeutic landscapes were the ways in which participants were located in an inward facing circle where they could all see and were close to one another. Because Tai Chi required participants to conduct synchronous movements in intimate cultural spaces where they were physically located in close proximity, it encouraged the development of rapport and meaningful social interactions (e.g., laughing, joking, and smiling) amongst the group. Whilst many of these social interactions may also be present in other activities patients engage in at the hospice, some interactions– especially physical touch - were unique to Tai Chi. In this way, Tai Chi may present opportunities for unique social interactions between participants that may not be available in other hospice activities. The following field note exemplifies the ways in which participants used physical touch and verbal interactions to form meaningful connections with each other:

The physio guided the participants through a movement where they were to move their arms in a circular motion in front of their body while imagining that they were polishing a crystal ball. As Rachel engaged in the movement, Christie (who was sat next to her) turned in her direction with a smile, looked her in the eyes and joked while lifting her foot up: "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 and in doing so set off a chain of laughter that travelled around the circle in which the patients, volunteers, and physiotherapists were sat. [observational field note]

As Judy commented, these interactions were meaningful in that they represented "the light and the uplifting that we're bringing into each other's lives" [interview 1]. Furthermore, the circle was also something that represented Tai Chi as an inclusive activity in which they could form connections with one another. Again, in the words of Judy: "it's like the reason King Arthur had the round table, nobody's in charge, you're all equal in a circle" [interview 1]. This inclusivity was further reinforced by the multifaceted aspects of Tai Chi (e.g., meditative routines, breath work, and choreographed movements) which enabled participants to take part in the activity in different ways. If some just wanted to sit and listen to the music or engage in imagery they were free to do so. In these ways, regardless of the aspects an individual chose to engage in, Tai Chi could still foster a sense of togetherness and connectedness amongst the group. Commenting on the uniqueness of Tai Chi as an inclusive activity which brought all patients together at the hospice, Debbie recounted:

> I think it's nice that they [the physio's] gather us, you know. Cos when we come, we're all doing different things, everybody's doing different things. I think it brings us back together as a group and I think it's good before lunch… I think that a circle is always like a circle of friends is a good way to describe us, cos we only meet once a week for a few hours so were not, we know people more than others, you know, but we are all part of a group and I think the Tai Chi sort of reiterates that cos we come, you know, we come together as a group to do it …I think we are connected as well because people just do it. You know, there's nobody that goes "ahh" and even if they don't want to do it, they're quite happy to take on board the music and the, you know, the sounds, joining in your own way but if you're joining in, is you're not doing, it doesn't matter, cos you still feel part of the group. [interview 2]

In these ways, participating in Tai Chi was a way for participants to further connect and reaffirm bonds that they had made with other patients throughout their time at the day therapy unit. Indeed, building a sense of relatedness, companionship, and camaraderie with others during Tai Chi was particularly important for participants who often report feelings of social isolation (Ek & Ternestedt, 2008; McKechnie et al., 2007). Chapter 5 demonstrated how many of the participants in this study lived alone and/or were often confined to the four walls of their house due to their disease-

related physical decline. Going to the hospice was often the only time these participants got out of the house and spent time around others. In this way, Tai Chi was seen as an extension of the hospice experience more generally in that it was an activity through which participants could temporarily alleviate feelings of social isolation and loneliness. They experienced this by connecting with others in meaningful ways. As Jane shared: "this [Tai Chi] is a way from being in isolation on your own, you see" [interview 1]. Similarly, Gloria explained:

> G: You do [interact with others during Tai Chi], which you don't if you're on your own at home do you? If you're on your own all day. Like I'm not sure what I'm going to do on a Tuesday now. My daughter goes to her Multiple Sclerosis class, I think she'll be arranging for one of the in-laws or somebody to come and sit with me, even if you only have somebody to talk to, it's nice. Otherwise you feel cut off completely.
>
> AB: And does Tai Chi help to deal with that?
>
> G: Yes, it's nice. [interview 1]

Through experiencing a sense of inclusivity, togetherness, and connectedness with each other during Tai Chi, improvements in participants' social QOL can be understood as the product of an enhanced psychological well-being. That is, as the belongingness hypothesis (Baumeister & Leary, 1995) proposes, participants in this study exhibited the inherent human need to form affectively pleasant and stable connections in which there existed reciprocal concerns for each other's wellbeing. In discussing Kimberley Brownlee's philosophical work on belonging, Monbiot (2017) presents three different types of belonging: (a) belonging with (e.g., characterised by symmetry and reciprocity in relationships); (b) belonging to (e.g., membership of groups); and (c) belonging in (e.g., feeling at ease within our social surroundings). The data suggests that – in different ways and magnitudes - participants experienced all three forms of belonging. Because it was a time in their lives in which many felt emotionally vulnerable and under threat, the importance of forming these types of bonds was magnified (Rofe, 1984). Thus, in line with Ryff's (1989a, 1989b) eudemonic conceptualisation of well-being, engaging with others and forming meaningful social connections during Tai Chi was able to promote growth, thus enhance psychological well-being in participants in this study through the

development of positive relations with others. Thus, in accordance with Calman's (1984) gap theory, participants were able to improve their QOL through closing the gap between their present reality (e.g., a life in which they sometimes felt isolated or disconnected) and their aspirations/hopes (e.g., the need to feel connected to others). This supports notion that even when an individual's life is unfulfilled in one domain (e.g., a poor physical QOL due to constant decline), they are still able to grow, thus experience a good QOL in other domains (e.g., socially, through fostering meaningful social connections with others) (Calman, 1984).

Whilst most participants experienced growth through meaningful social interactions during participation in Tai Chi, some experienced social interactions that negatively impacted on perceptions of their QOL. This was because for some participants, Tai Chi was seen as an activity in which they could foster a quiet, inward connection with the self as opposed to a social occasion in which they interacted with others. These two understandings of Tai Chi were often incommensurable as interactions such as joking and laughing were directly at odds with, and were seen as a source of disruption to, being mindful. For example, a conversation with Debbie during an interview highlights these tensions:

AB: And the next question I had was that sometimes I've observed people smiling or joking or laughing. Would you say that there's an element of humour or light-heartedness in the Tai Chi sessions?

D: There is in the sessions, yeah, erm, sometimes it annoys me. It annoys me when Lisa laughs or people do that, but then I have to be generous in that it's our group, it is relaxing and whatever and some people laugh in situations they don't always they don't always, they laugh cos that's their coping mechanism. I suppose I do think 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, you know, I wouldn't ever say I don't like it, but it is disruptive in a way, I find then I have to focus back, but then I, you know, 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, cos they're not sure if they're, or they don't 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. [interview 2]

In this way, for some participants the disruptions caused by laughing and joking during Tai Chi sessions represented an interruption to, or "uncoupling" of, the pleasant rhythms that were associated with, and experienced through, the pleasures of mind-body respite (see previous chapter) (Phoenix & Bell, in press). That is, some participants linked Tai Chi with the ability to be in the moment through focusing on the qualities of gentle movements, imagery, and nature. Certain social interactions, however, uncoupled this synchronicity through undermining participants' ability to achieve this.

7.2. Mutual Empathy and Reciprocal Support

Whilst some participants talked about feeling a sense of social isolation as a result of living with advanced, incurable disease, others alluded to how they experienced emotional isolation. This occurred because they felt as though "healthy people" could not comprehend what it was like to live with terminal illness (see chapter 5.1). From a relational cultural theory perspective (Jordan, Kaplan, Miller, Stiver, & Surrey, 1991; Jordan & Harding, 2002), participants' experiences of emotional isolation culminated through others' misunderstandings of their illness. This lack of comprehension may have represented what Jordan and Harding (2002) call irreconcilable "empathic failures" (e.g., an inability to empathise with another's situation) which caused frictions and "disconnections" in relationships. In consequence, because participants felt alienated from others, stigmatised, and therefore unworthy of care and attention, it seemed as though they were prone to withdrawing from relationships as a way to protect themselves from "a pervasive sense of inefficacy and depression" (Jordan, 2000, p.1008).

What was unique about participating in Tai Chi within the cultural setting of the hospice – especially when compared to other environments (e.g., home and hospitals) where they were surrounded by people who found it difficult to grasp the lived reality of terminal illness - was that all participants had an implicit, mutual understanding and respect of what it was like to live with advanced, incurable

disease. Whilst participants did not explicitly talk about or dwell on their disease when participating in the Tai Chi sessions, they seemed to appreciate the unspoken shared connection that it created amongst them. That is, patients demonstrated a mutual empathic understanding towards each other during Tai Chi sessions through how they appeared to be naturally attentive to, and readily understanding of, the needs of other patients around them. This was particularly evident with regards to how they understood the ways in which disease-related impairments may negatively impact their participation. For example, it was not uncommon for patients to signal for help when they noticed somebody struggling (e.g., through pain, breathlessness, or lethargy) during Tai Chi sessions:

> It wasn't long after Tai Chi had started that Shannon – a patient with pulmonary arterial hypertension and lung disease – rapidly became breathless. In contrast to how she enthusiastically started the session, she was now visibly out of breath and struggling to keep her upright posture. Another patient was quick to notice the struggles that Shannon was having and, without making too much of a fuss, waved her arms and pointed to Shannon as a way to signal to one of the nurses passing through the session that she wasn't doing so well. It was in no time that the nurse was sat at Shannon's side having a whispered conversation, helping to ensure that she was ok. [observational field note]

The following field note offers another example of the ways that participants demonstrated an empathic understanding and attentiveness to others' needs during Tai Chi sessions:

> Just as Tai Chi was coming to an end and patients were sat drooped into the back of their chairs savouring the relaxing music, the calls for lunch were sounded. Judy proceeded to slip on her shoes and got up to walk towards the dining room. On her journey she noticed another patient who was struggling to get up out of their chair and offered her hand out in assistance in pulling him up. [observational field note]

In these ways Tai Chi was an activity that brought patients together under a positive collective identity in which they felt safe and cared for (Lehardy & Fowers, 2018). This is because it provided a venue in which they could connect with other

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patients who had a genuine and experiential understanding of terminal illness and in doing seemed to act as a way for them to gain a sense of solace from a life in which they often felt misunderstood (Lehardy & Fowers, 2018). The phrase: "being in the same boat" was frequently used to demonstrate how Tai Chi was an activity which allowed participants to reinforce the collective identity that they developed at the day therapy unit. For example: Judy recounted:

> [during Tai Chi] we're all in the same boat, we might not all have the same disease or the same type of 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, like protected probably where we know no-one else is ill as we are but that's not what's important. You know there's always someone there will talk to us if you want to talk and listen but if you just want to have a laugh and a giggle and whatever, everybody's there for you. [interview 1]

As such, taking part in Tai Chi at the hospice helped the participants to feel understood in a social context embodied by mutual empathy and reciprocal support. This was important because the progressive nature of terminal illness changed how participants looked and felt about themselves as well as how they thought their friends and family perceived them. This created a sense of feeling different to one's past self and to others. However, the collective identity and group interactions during Tai Chi helped to (re)shape participants' understandings of what it meant to live with advanced, incurable disease through the ways in which it normalised the illness experience, thus relieved feelings of being different. A conversation during an interview with Christie demonstrates how Tai Chi was perceived as an activity in which she could feel normal and accepted in a world in which she often felt ostracised and misunderstood:

> C: In activities and things and the Tai Chi you don't, I don't personally, it might be different from other people's perspective, *but I don't feel as ill* cos everybody keeps telling me "you're doing fine, you're doing fine" and I'm still holding onto the fact that I've got 6 months to live which was a long time ago.

> AB: How have your experiences of being able to do activities such as Tai Chi in a group with other people been?

C: It's nice because I don't go anywhere, only Laura my befriender takes me, so 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, it's not the same going out with a befriender. [interview 2, emphasis added]

The importance of doing something new around other people who were similar to themselves was highlighted through the juxtapositions that participants made between the differing experiences they had of doing Tai Chi at home compared to in the hospice environment. As Jane recounted during an informal conversation:

It's [Tai Chi] about being with other people. I have the CD [of Tai Chi music] at home – [the activities co-ordinator] gave it to me so that I can listen to it in my own time - and I sometimes sit there picking the apples from the tree, but it's not the same on your own. It's just nice to have the physio's and other people around you doing something new. Since being away from [the hospice] the last time I was here, *I missed that, you know, other people that are like you* – but we don't talk or mull over our problems. [emphasis added]

Accordingly, participating in Tai Chi at the hospice was something that enabled participants to develop mutually empathic and empowering relationships with each other. The relational cultural model (Jordan et al., 1991) proposes that it is these types of bonds that facilitate human growth and flourishing. Again, this would fit with Ryff's (1989a, 1989b) notion of "self-actualisation" which proposes that fostering positive relations with others – that is, warm and trusting relationships in which one can experience and provide love, empathy, and affection – is important in enhancing psychological well-being. Thus, it is possible that the improvements in participants' perceptions of their QOL occurred through the mutually empathic social interactions that took place during Tai Chi sessions.

Mutual empathy of what it was like to live with a terminal illness (as described above) formed the basis through which participants gave and received social support to one another during Tai Chi sessions. Within the literature social support is a broad term that can relate to structural (e.g., mere existence of relationships) or functional

(e.g., resources provided in a social network including informational, instrumental, and emotional) types of support (Helgeson, 2003). Specifically, the functional role of emotional support appeared to be the significant driver in ameliorating the QOL of participants in this study. This refers to having people around you that are willing to listen, care, sympathise, reassure, and make one feel valued and loved (Helgeson, 2003). When stressors are uncontrollable – which are ultimately the case for many of the problems associated with terminal illness - it is postulated that this type of support is most beneficial (Helgeson, 2003). Indeed, Tai Chi was seen as an activity in which participants were able to reach out to and care for/sympathise with one another in ways that made them feel valued. This provided great comfort from the stresses, anxieties, and stigmatisation that their disease caused them. As Christie recalled:

> the only way I can express it is, it's 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, roughly, all got cancer or carer problems, or something. And they've been trying to get me into some groups, and I think, it's alright, 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. [interview 1]

Thus, the protective value of group membership experienced in Tai Chi was an avenue through which participants could improve their QOL through opening themselves up to receiving emotional support from other people through interactions characterised by positive communication, empathic understanding, encouragement, and care and respect. Furthermore, as well as being able to receive support from others, Tai Chi sessions were also an opportunity for participants to reciprocate the care and support they received. Being able to give back to others at this stage of their illness was important to participants. This was because having advanced, incurable disease represented a time in most participants' lives where they felt as though they took from and were a burden to others (e.g., friends, family members, health care professionals). Many participants talked about feeling as though they drained practical, financial, and temporal resources from others whilst not being able to balance these relationships through social reciprocation (see chapter 5.1). Tai Chi,

however, was a platform through which they could give back and feel of use and service to other patients in meaningful ways. For example, Judy reflected on how she felt Tai Chi sessions were an opportunity in which she could help others:

> [during Tai Chi] I feel I'm part of something that benefits to everybody and it's nice to feel that you are doing things that will help other people even, 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 and then between the two groups as well and it's just that respect and wishing each other wishing the best for each other. [interview 1]

In these ways, Tai Chi sessions presented participants with the opportunity to inhabit what Frank (1995) calls "dyadic bodies". These types of bodies are communicative and empathic, taking on an "other-relatedness" which is "concerned with how the shared condition of being bodies becomes a basis of empathic relations among living beings" (Frank, 1995, p.35). Accordingly, the ways that participants' shared understanding of illness acted as the basis through which they could support each other during Tai Chi sessions presented an:

> opening to becoming a dyadic body because the ill person is immersed in a suffering that is both wholly individual-my pain is mine alone-but also shared: the ill person sees others around her, before and after her, who have gone through this same illness and suffered their own wholly particular pains. She sees others who are pained by her pain. (Frank, 1995, p.36)

Further examples of how participants embodied dyadic bodies during Tai Chi sessions were evident through what Judy called the "warmth of healing" [interview 1]. For example, the following extract from a field note demonstrates the way through which physical touch was used by participants during Tai Chi as a way to care for and look after one another:

> Despite being mid-September, the perpetually raging radiators meant that the room in the Day Therapy Unit was typically hot. As the Tai Chi session was coming to an end Gloria – who was sat to the left of me – quietly whispered:

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"I'm warm" as she slowly and steadily took off her cardigan to prepare for the final relaxation technique of the session. Gloria was sat next to another patient who, as a result of peripheral neuropathy from chemotherapy, had been talking with Gloria earlier on in the day of how her hands and feet were perpetually cold. Just before Gloria laid back into her chair she gently caressed this patient's hands with hers whilst saying: "I'm warm and you're cold." They then exchanged a friendly and warming smile as Gloria removed her hands and lay back in her chair. [observational field note]

Ultimately, the shared identity and mutual empathy that pervaded Tai Chi sessions at the hospice provided a platform/foundation through which participants could give and receive genuine, useful and meaningful emotional support. The dyadic bodies of participants which ensued represented the ways in which illness was somewhat of a "craft" for participants (Frank, 2003). According to Frank (2003, p.248), the craftwork of illness, is an ethical and moral process in which "illness survivors respond to others' suffering with a self-consciousness of their own vulnerability". He goes on to add:

> To put it most simply, from 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. We need to accept what popular thinking wants to deny: Suffering is the call to and preparation for works of further service. (Frank, 2003, p.249)

Thus, Tai Chi provided an activity which allowed participants to engage in the craftwork of illness. By tuning into - rather than avoiding or isolating themselves from – the commonality shared between one's own and other patients' disease-related suffering, Tai Chi worked as a way for participants to develop a sense of self-compassion (Neff, 2003). That is, through opening themselves up to support from others and allowing them to reciprocate such, it engendered a desire to heal and relieve the grief and misery that was associated with their illnesses through adopting a kindness towards the self and others (Neff, 2003). This highlights the uniqueness of the hospice as a cultural setting in which Tai Chi was located because it allowed participants to develop a "social esteem" and "relational resilience" in which they worked together to cope with the traumas of their illness (Jordan & Harding, 2002).

These findings, therefore are in line with social comparison theory which postulates that when in stressful and traumatic situations, because they are better equipped to provide more relevant support and respond meaningfully, individuals will turn to those who are similar to the self (e.g., experiencing the same or similar situations) for social support (Cohen & McKay, 1984). Thus, even in the face of extreme adversity and trauma, participants were still able to enrich their QOL through working with others who were similar to themselves as a means to buffer the feelings of empathic disconnections and stresses that they experienced in their everyday life.

7.3. Creative Non-Fiction: "The Craftwork of Illness"

"I've got some good news for you, Christie!" the oncologist beams as he opens the door to his office. "You know that your cancer markers have been hovering between 90-100? Well, they've 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.

"Are you ok?" asked the oncologist, "you don't look as pleased as I thought you would be."

"Yeah, no that's great news. Thanks so much." Christie replied hastily whilst doing all she could to avoid eye-contact.

"Great! I *knew* you would be over the moon. It's not 'gonna cure you, but it certainly looks like you'll live just for that bit longer now!"

"He's totally missed the point," Christie thinks to herself as she slouches into the back of the chair in the doctor's office. In receipt of such news the only thing she could think of was "yeah? So what?" After the appointment ends, Christie lets out a sigh as she adopts a slumped position in the waiting room chair at the hospital. 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 seemed that every time she came to the hospital and met with health professionals that she was treated as one big walking, talking tumour marker. But living with this blind, emotionless alien savaging her body and mind from the inside out is much

more than being a tumour marker. For Christie, however, these people just don't seem to get that. She understands that they are only trying to help her, but she can't shrug the overwhelming sense of being dehumanised by it all.

As she arrives back home, Christie rummages around her bag to find her front door key. She lifts it up and inserts it into the lock. Sooner than her wrist turns to open it, her heart drops. Her eyes swell as a salty teardrop slides down her cheek and into her mouth. The taste of saline, of which she has become well acquainted with, enters her mouth one drop after another. Sniffling and gulping, 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 her surrounded by friends she once had. Right next to it is another of her and her siblings on a holiday when they were young. "Where are these people now?" she questions herself. She knows they are still alive and well, in fact, 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 in deep, dark, parts of her consciousness she continues her all-too-familiar lonesome trek up her stairs and into her bedroom where she draws back her bed sheets and slumps her body underneath it. She pulls the cover over herself tightly and hides in it as though it took her into another world. This is all Christie wants to do nowadays, hide in bed. Get up, have her main meal, and then back into hiding. This is where she will stay wrapped up until she has another one of those dehumanising hospital appointments to attend. Maybe it would be better if she didn't wake back up; she doubts anyone would notice anyway.

Being in bed gives her plenty of time to ruminate. She thinks back to when she was a teacher at school. What swine's those kids were at times. But at least it was a time in her life where she was able to inspire and care for people. Nowadays all she feels she does is take up and wastes other people's time and space.

Later that week at the hospice

Christie slowly makes her way into the main room of the hospice's day therapy unit, taking short and 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 at all 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.

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

"She's already sweet enough!" Jane - who is another patient at the day therapy unit -interjects with a cheeky grin.

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

"So 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. You know the sorts," Christie groans.

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

No more was said about the matter. No elaboration on the doctor's dehumanising appointment, the week she had spent confined to her mattress, or just generally being fed up. In fact, none of that was needed. Christie knew that Jane has been there and done that. Nothing's new here. Nothing's shocking.

12.20pm

Dressed in their navy-blue trousers and white tops, the physiotherapists bounced down into the main day therapy room with their usual smiles and bubbly auras. The place looked like a bombsite. Over across the far end of the room sat a group of gentlemen sipping from cups of Yorkshire's finest 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 from them, hands sticky and messy from the glue they were using to make "Thank You" cards for local fundraisers. As for Christie, she was still sat next to Jane trying to finish the day's crossword. People were everywhere and doing all sorts.

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

A series of nods, "oh yeses", and smiles followed as most patients proclaimed their interest. The volunteers knew what this meant; the weekly re-arranging job, trying to get the room and the patients in it ready to take part. As they cleared out tables from the middle of the room, re-positioned stray Zimmer-frames, and started to position chairs into an inward-facing circular arch, the room transformed from a fragmentation of different activities to a unified and organised formation. As the Tai Chi music started to elevate in volume, patients sat down in touching distance from one another. Christie realised that in the midst of the chaos that was all part and parcel of setting up Tai Chi, she found herself next to Lee, a recently admitted patient who she had not yet had chance to speak with. Before moving into the first movement, the physio takes a chance to remind the patients:

> "do what feels right for you. If you just want to sit back and listen to the music and imagery you are more than welcome. If you want to take part in the movements too then even better. 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, spreads them outwards, and then brings them back in again. As she turns to her right, she sees Lee's arms mirroring hers as they move in perfect time and harmony, almost as though they were two parts of the same system. As they extend their arms outward one more time, the tips of their fingers almost touch, but with a careful adjustment, Lee avoids collision, bringing his hands back towards himself as they both exchange slight grins.

As patients 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, working towards the same goal. As she scans the room and see's all of the other patients joining in with the same movement, she realises that for the last week the only people she has come into contact with are medical professionals. How nice it is, then, to be so closely surrounded by different people. Actually, these people are very much the same, they've all got an incurable disease like her. They – like Jane earlier on in the day - understand what she is going through. Everybody's together for this half an

hour, sailing in the same or a very similar 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 patients:

"now imagine you are picking up a light and fluffy cloud on a bright summer's day. Feel it as it gently caresses your fingertips like candy floss and imagine how fresh the air smells as you slowly bring it up towards your head, across your bodies, and up towards your face. Then watch it as you push it back down beneath you and pick up another." She further encouraged: "if you see someone else up there with you, give them a little smile."

As Christie twisted her torso, cloud in hand, she caught the eye of the physio and exchanged a warm, healing, and sincere smile as they became lost in each other's glances. This feeling seemed to reverberate around the circle, patient by patient, as the smiles bounced from face to face intimately touching the souls of patients in ways that no pill ever could. As she pushed her cloud away she felt a light bump on her arm.

"oi you, get off my cloud," Jane joked in her soothing voice 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 the patients shared laughter and jokes the physio smoothly used this to transition into the next move: "right then, we better put these clouds down before they get out of hand."

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 draws to an end the patients slowly ascend and make their way into the dining room where their dinner awaits.

"I feel good after that," Lee beams to Christie as he stands up next to her.

As they slowly walk towards the dining room together she replies: "so do I, it's nice to do something like that with everyone together before lunch,"

"It is, isn't it?' reaching his hand out, he continues: "I'm Lee, sorry I haven't had chance to introduce myself yet, it can get a bit hectic in here at times."

"No need to apologise, I'm Christie."

As they pull their chairs out at the dining table Christie feels somewhat bittersweet. She feels healed by the company she has just experienced and the new friend she has gained. 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.

7.4. Summary

In this chapter I described the theme of social engagements to demonstrate how Tai Chi was able to facilitate growth, thus promote psychological well-being, in participants through offering an avenue in which they could experience *meaningful social connections* and *mutual empathy and reciprocal support.* Similarly to the previous chapter, I firstly used conventional realist tales to demonstrate to the reader how Tai Chi was an inclusive activity which brought participants together under a common goal in ways that other activities at the hospice did not. Because it brought participants together who had a shared understanding of what it was like to live with terminal illness, a mutual empathy between participants pervaded sessions. This provided a unique platform through which participants were able to reach out to one another in reciprocal ways through the giving and receiving meaningful, genuine, and useful support. Following these realist tales, I utilised the storied approach of creative non-fictions to bring to life how social engagement played out in the context of the hospice and how this was able to improve the QOL of participants. Hopefully, this was able to move readers in evocative and emotional ways.

Chapter 8: Case Studies of 'Outliers'

8.0. Overview

The findings that I have presented up until this point have focused on the positive ways in which taking part in hospice-based Tai Chi affected participants' perceptions of their QOL. Indeed, chapters 6 and 7 are representative of the common experiences that were shared by most participants who took part in this study. That said, it is important not to gloss over the negative and messy experiences that – although were not as frequently reported as those in the aforementioned chapters - were associated with engagement. In chapter 4.7.3 I drew on work by Phoenix and Orr (2017) in making the case for the importance of attending to what they called "outliers" (i.e., non-dominant data that challenge and contradict the main themes that are sculpted through data analysis). In part, it is attending to these types of "negative" or "deviant" cases that is an integral facet of ethnographies, especially because they are able to enrich, and do justice to the complexity of, our data (Brewer, 2000; Fetterman, 2010). Whilst the data presented here is representative of only a minority of participants' experiences of Tai Chi (in fact, the first sub-theme is almost entirely based on the accounts of 1 participant) it is possible that these views and experiences may represent those of patients who did not take part in this study.

The "outliers" presented here, therefore, are represented by two, separate case studies. As Stake (1995, p.12) recognises, a case represents a 'specific and bounded (in time and place) instance of a phenomenon selected for study'. In the context of this chapter, the distinguishing features of the cases that have been selected are that they consist of accounts told by a small number of participants (n= 4) with advanced, incurable disease who did not always find participating in Tai Chi easy, beneficial, or enjoyable. These are presented in two different types of cases studies. The first case study adopts an instrumental approach (e.g., the study of a singular case with regards to participation in Tai Chi) and is represented through the theme 'unmet expectations, lacklustre experiences'. This case study is based on the experiences of one participant in this study who simply did not experience Tai Chi to be beneficial to his well-being or QOL. The second case study adopts a multiple case study approach (e.g., the study of more than one case with regards to

participation in Tai Chi) and is represented through the theme 'mastering the art'. This case study is based on the experiences of 3 participants and refers to the complex learning process that they had to undergo for them to be able to benefit from Tai Chi in the ways that are presented in chapters 6 to 7. The rationale for using these types of case studies in this chapter was to richly answer 'how' and 'why' participating in hospice-based Tai Chi was not always a positive or easy experience for some participants (Sparkes & Smith, 2014).

8.1. Case Study 1: Unmet Expectations, Lacklustre Experiences

In this project, there was 1 participant (Michael) who was indifferent about Tai Chi. This was because he felt as though it pertained no benefits to his well-being or QOL. Speaking of his lacklustre experiences of Tai Chi during an interview, he told me: "I'll do it [Tai Chi], but it doesn't have much effect on me … I just do it, go through the motions". Specifically, despite Tai Chi being a multifaceted activity in which many participants experienced benefits from in some shape or form (i.e., whether this was in regard to the music, imagery, or movement), for Michael, this was not the case. Rather, he gave numerous examples of how he found it difficult to benefit from any aspects of the Tai Chi. For example, in chapter 6, many participants spoke about how the gentle movements of Tai Chi provided them with a sense of embodied peace and relief from the physical illness-related traumas that plagued their everyday life. Whilst Michael recognised that Tai Chi was *supposed* to provide him with similar visceral sensations, a conversation that I had with him in an interview showed how in practice he experienced nothing of the sort:

> M: *I think that a lot of it is to help you relax* but also to do a certain amount of exercise so that your body's not seizing up *but mine's seized up so I find it difficult to do it*

> … AB: Yeah and you spoke a little bit about relaxation there, how have you experienced the relaxation part of Tai Chi?

> M: Erm, I get the, the lady [complimentary therapist] who does relaxation things here, you know, I have sessions with her and I think that I get more out of what she does, the actual work that she does on my back particularly is very good. It's not Tai Chi, it's you know, I don't think she would say it's Tai Chi but it's a similar sort of thing.

AB: Yeah, and how would you say that you have experienced the relaxation in just the Tai Chi sessions themselves?

M: Erm, *there's very little difference from starting the session to finishing it, it doesn't relax me.* Sorry if this is awkward. [interview 2, emphasis added]

The above quote suggests that although Michael understood the "affective possibilities" (Andrews et al., 2014) that were supposed to be available through participating in Tai Chi (e.g., a state of embodied peace through relaxation) he did not experience them. In this way, the expectations that he had thought possible through taking part in Tai Chi were unmet, leaving him with a sense of being underwhelmed. Furthermore, there was also a sense that he felt as though his body was too far deteriorated (e.g., muscles being too tense) for him to be able to benefit from Tai Chi in the same ways that other participants seemed to. Rather, he noted how he found other therapies (e.g., massages) that were offered by the complimentary therapist more conducive to improving his QOL. During an interview he expanded on this and shared:

AB: Have you had any benefits through doing the Tai Chi here? Any at all?

M: I can't say that I have to be truthful. Again, I could compare it, if I could compare it with the massage that I get, when I finish the massage and I go back to my chair and sit back, and go home, when I go home there's quite a marked difference in the way I feel, but with the Tai Chi, there's nothing, I don't get that same. [interview 2]

As well as not experiencing improvements in his QOL through taking part in the physical movements of Tai Chi, Michael also spoke about how he struggled to benefit from the imagery aspect of sessions. Speaking of these difficulties, he told me how he found this part of Tai Chi sessions as somewhat silly and humorous:

AB: how have you experienced the visual or imagery aspects of the Tai Chi?

M: Erm, you mean the trees and the?

AB: Yeah

M: Erm, I find it humorous, it's difficult to say. When I'm doing it, you know, I don't think in terms of tree growing … [I] don't really experience anything other

than just that I'm doing this thing that I'm not used to doing, seems silly and perhaps a bit, you know, ungrateful but I'm, I've never ever been into it. [interview 2]

Comments made about the unusualness of Tai Chi were often made by participants who had only recently started participating in sessions. For example, during her first interview (after only partaking in Tai Chi twice) Jane spoke about how she saw the intertwined movements and imagery that were part of Tai Chi as peculiar. She commented on how she felt that she and other patients used humour to mask their self-consciousness of taking part in such a strange method of physical activity:

J: you can find it [visualisations during Tai Chi] amusing as well. I mean, it's your attitude, you see, I mean, you know, the lady next to me last time, mother and daughter were here, you know, it's a case of "don't pinch my apple", you know. And you see, it gives some people a bit of sense of humour because... I tell you what's it is, its self-consciousness, that's what it is

AB: Yeah? In what way?

J: Well when you're moving and doing this, which you don't normally do, and everybody else is doing it, you're a bit self-conscious of what you're doing. Cos it's not moves that you would do in ordinary in life. You know, you have to, if you're going to do it, you have to have a little session of sitting down and concentrating on it. And I think that's what it is. Cos quite a few smile while were doing it, and it's not, it's not mocking it in any way, or belittling it, it's just that you find it strange, you know, and perhaps it's in the group, perhaps you're a bit self-conscious of the movement. [interview 1]

Chapter 6 showed that most participants were able use movements and mental imagery during Tai Chi sessions to foster a peace of mind that assisted them in (re)learning and (re)shaping how they perceived themselves and their illness. For Michael, however, this was not the case. Instead, as a deeply religious man, he told me how he turned to his religion (as opposed to Tai Chi) as a vehicle to experience solace from disease-related distress:

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M: the meanings in life that I want, that I'm looking for, is more concerned with my faith than with physical activity, I mean, you go through life as a Christian following a, you know, a sort of set pattern of life, and in meditating you sort of gain something from the meditation, the sense of awe, the sense of peace, erm, being content, you know, in this thing, erm with, you find a sort of strengthening of yourself to face what's coming, you know, what we all know is coming.

AB: So do you feel that Tai Chi impacts your QOL in any way whatsoever?

M: Not really, not really, if someone came to me when I was working, you know in my study, and *asked me how they could find peace of mind or comfort in life*, *or a sense of meaning, Tai Chi certainly wouldn't be the top of the list.* I'm sorry if this is disappointing you. [interview 2, emphasis added]

In summarising his experiences of Tai Chi, Michael told me:

to tell you the truth I find it a bit boring [laughs]. Don't enjoy it, may not be the answer that you want, but it, to me it's a bit boring, yeah … I don't dislike it, but you know, I wouldn't be the first in the queue to do it either. [interview 2]

One may pose the question that if he found Tai Chi a boring activity which in no way ameliorated his QOL, what drove Michael to take part in Tai Chi over such prolonged periods? In answering this question, the influence of the social-cultural context in which Tai Chi was located provides interesting insight. That is, Michael told me that he took part in Tai Chi because he felt pressured:

I do it simply because they do it, you know, it's peer pressure if anything, erm, I perhaps look for a, you know, bit of exercise, but other than that I don't expect very much out of it. [interview 2]

The peer pressure which underpinned Michael's motives for engagement in Tai Chi may be demonstrative of the subtle social influence of compliance. According to Cialdini and Goldstein (2004, p.592), "compliance refers to a particular kind of response—acquiescence—to a particular kind of communication—a request". Compliance with tasks and activities that individuals do not wish to engage in are often the product of "descriptive norms" (i.e., taking part in an activity because it is what is typically done within a certain social context) (Cialdini & Goldstein, 2004).

Indeed, Tai Chi was an integral aspect of the day's routine at the hospice and it is possible that even though he experienced no benefits through taking part, Michael's engagement was an example of conforming/succumbing to perceived pressures. This may be summarised by the notion of: "I don't want to do Tai Chi but if everyone else is doing it, then I should probably do it too". This may have been because he did not want to disrupt routine or belittle sessions that he knew other patients enjoyed and benefitted from. In this way, one could argue that feeling as though one could not opt out of Tai Chi sessions was counter to the patient-centred ethos (as seen in chapter 5.2) that was espoused in the day therapy unit.

The above data challenges the notion of exercise (and specifically Tai Chi) as a form of "medicine" for participants with advanced, incurable disease. This plays on the idea that medicine is universally good for and enjoyed by everyone (Nesti, 2016) and its logical extension is the over-simplistic and unquestioned portrayal as exercise being a cure for all ills (Williams et al., 2017). Williams et al. (2017) warns against the dangers of uncritically accepting this concept, especially as the relationship between exercise and health in the world of chronic illness is a complex and morally contested topic. With Michael's experiences in mind, therefore, it may be better to think of hospice-based Tai Chi as being "mostly good and good for most; but not always and not for all" (Williams et al., 2017, p.452).

Critical reflection 9: Being attentive to difference

In a conversation I had with the physiotherapy team today, we spoke about how it had been difficult to recruit participants who did not always take part in, or enjoy, Tai Chi sessions at the hospice. We are aware that whilst most patients really enjoy Tai Chi, it is not for everybody and agreed that it is pivotal to include the voices of these types of individuals in the project. However, when I approach them, I get the impression that because they don't take part in sessions, they feel as though they cannot offer any insight into their views and experiences of them. At the moment, only one participant who is part of the project has spoken about Tai Chi in a predominantly negative way. I'm not sure if I have enough time left in the field to recruit many more participants, so I am using this patient as a "deviant case", or "outlier", to try and understand in as much detail as possible why he doesn't enjoy Tai Chi. More importantly, in our next interview I think it's important to try and understand why he still takes part in Tai Chi even though he does not buy into it. I plan on including this case in my write-up in the hope that it can be used to build a more representative and rigorous picture/analysis of the different perspectives that exist with regards to participation in Tai Chi within the cultural context of the day therapy unit.

8.2. Case Study 2: Mastering the Art

Throughout chapters 6 and 7, the positive aspects related to participants' engagement in Tai Chi were presented as uniform and smooth, almost as though they turned up and immediately benefitted from the pleasures of mind-body respite and social engagements. However, this was not always the case. To only present it as such, therefore, would be to gloss over and iron out the complexity and messiness of the processes through which some participants experienced and benefitted from Tai Chi (Krane, 2016). To quote Krane (2016, p.472): "life is messy and so too are our data". Indeed, this quote captures the "messy" ways in which participants came to benefit from taking part in Tai Chi. Thus, for many participants, improvements in QOL that were engendered through participation may be best understood as a complex journey in which it took time for them to assimilate to an

unusual form of physical activity. That is, it was not uncommon for participants to be sceptical of the value of Tai Chi when they first started. As some of the quotes above showed, Tai Chi was initially experienced as strange and out-of-the-ordinary; some participants couldn't understand what it was all about and what could be gained through doing it. It was only after repeated engagements in Tai Chi that they started to see and feel its benefits. A note that I made after an interview with Gloria exemplifies this:

> Thinking that the interview was finished and there was nothing else left to say, I switched off the Dictaphone. We were sat in the dining room waiting for a nurse to come and help with Gloria's oxygen machines so that she could re-locate into the main room of the day therapy unit. To pass the time I asked her how she initially viewed Tai Chi in her first few weeks and how this had changed over time. To this she responded:
>
> "I thought it was a waste of time but then started to do it and saw that it was helpful." [field note extract]

Similarly, in her second interview (about a month after our first) Rachel told me:

> at one time, I wouldn't have been into all that [Tai Chi], no, but, now that I've actually done it and experienced it, and yeah, it's actually quite nice. [interview 2]

> From talking to participants, it appeared as though Tai Chi was perceived as more than just a physical activity (i.e., it entailed more than just moving the body). Instead, it was seen as somewhat of an art form which had to be mastered in order to benefit from. When they had just started taking part in Tai Chi, many participants spoke about how they felt as though they had to learn certain aspects (i.e., how to synchronise mental imagery with movements) before they could truly immerse themselves in, and ultimately benefit from, them. For example, when I asked Rachel how she had you experienced the visual aspects of Tai Chi, she told me:

> Well, I'm getting used to that, I'm still getting used to that. I have to remember all that and then do that in me own time, I suppose, as time goes on. But I suppose after 12 weeks, I'll know it all off by heart won't I... once I get to know

the story and the movements, I'll be able to do that myself. You know, it's learning that, what they're doing it, you know. [interview 1]

Furthermore, in the first interview that I had with Jane (about 2 weeks after she had been admitted to the day therapy unit), she spoke about how she did not experience any psychological benefits through taking part in Tai Chi:

I don't think it does anything to my mind, I think my minds gone actually. But as I say… this is my second session here, maybe this time I might be doing it, you see, I could change completely with my attitude. I might be, at the moment, I think I'm probably putting up a little bit of a wall, cos of what's wrong with me and I'm trying to be completely normal, you know what I mean? And these little things might be more important to me in a little while. [interview 1]

Initially, there seemed to be a reluctance in participants like Jane "buying into" Tai Chi. By the time I interviewed her for a second time (6 weeks later), however, she spoke at great length about the ways in which taking part in Tai Chi was able to provide her with many of the pleasures that were associated with mind-body respite, in particular, the benefits of being present in the moment (see chapter 6.1). That said, she offered the following caveat when talking about the processes through which she benefitted (and believed others could benefit) through doing Tai Chi:

So I think it's [Tai Chi] a good thing, but you, *it takes a few goes before you can get into that state.* [interview 2, emphasis added]

The notion that Tai Chi was an art that needed to be mastered before one could benefit, fits in with Griffin's (2017) conceptualisation of embodied learning presented in chapter 6.3. She draws of the works of Crossley (1995) and Mauss (1973) in proposing that this type of learning (especially in activities which are novel) is experientially based, thus the product of prolonged exposure and repetition. The data above appears to support these assertions in that the benefits (particularly those that resided within the bodies and minds of individuals) experienced through engaging in Tai Chi were the result of a complex and messy process in which Tai Chi had to be conducted repeatedly over time. Through repetition, therefore, participants may have developed "corporeal schemas" or "body techniques" in which they developed an acquired ability to benefit from Tai Chi in ways that could not be

experienced through taking part in one or two sessions alone (Griffin, 2017; Mauss, 1973).

8.3. Summary

In this chapter I presented two case studies that described the "outliers" (Phoenix & Orr, 2017) of this project through highlighting the complex, messy, and negative experiences that some participants went through as they engaged in Tai Chi sessions at the hospice. These extracts represented challenges to the narratives presented in the main themes between chapters 6-7. These painted hospice-based Tai Chi as a somewhat smooth and unproblematic activity which participants simply turned up to, completed, and benefitted from immediately. Through presenting outliers in the form of case studies, however, I was able to demonstrate that this was not the case, or at least not the case for all participants in this study. For some, Tai Chi was just not beneficial. Drawing on Michael's accounts in the case study of "unmet expectations, lacklustre experiences", I was able to show how his expectations of Tai Chi (i.e., being an activity in which he thought he would be able to relax) did not match up with his actual experiences of taking part. I also played with the idea that his persisted engagement in Tai Chi, therefore, was a result of peer pressure and conformity. Furthermore, in the second case study ("mastering the art") I was able to demonstrate how Tai Chi was best understood as a sort of art-form, or complex journey, which participants had to master before benefitting from. I used the ideas of "body techniques" and "corporeal schemas" (Griffin, 2017; Mauss, 1973) to show how, in many cases, the benefits of participation outlined in chapters 6-7 were the product of repeated engagements in Tai Chi, where participants had to assimilate into an unusual activity and *learn* the ways through which they could benefit. In doing so, these case studies present nuanced and alternative perspectives on the meanings and experiences that hospice-based Tai Chi had with regards to participants' perceptions of their QOL.

Chapters 6-8 provide empirical evidence that answered the first research question of this thesis: how did taking part in hospice-based Tai Chi impact on patients' perceptions of their QOL? With this in mind, utilising the social ecological model (McLeroy et al., 1988) as a guiding conceptual framework, the following chapter of this thesis shifts focus onto answering the second research question. This

is focused on exploring participants' views on Tai Chi, including identifying perceived barriers and facilitators to participation. Through doing so, it is hoped that we can begin to develop a better understanding of how such interventions can be made even more effective, practical, and accessible to patients with advanced, incurable disease.

Chapter 9: Enablers and Barriers

9.0. Overview

This section of the thesis focuses on answering the research question pertaining to participants' views of, and the perceived barriers and facilitators that they faced in relation to, taking part in Tai Chi sessions at the day therapy unit of the hospice. The social ecological model to health behaviours (McLeroy et al., 1988; Sallis et al., 2008) was used as a guiding framework through which to answer these questions. From analysing data from interviews and field notes, five themes were constructed which demonstrated how participation in Tai Chi was influenced by the interplay of factors which traversed multiple levels of engagement, including: intrapersonal, interpersonal, and the perceived environment. These are represented visually in figure 8 below.
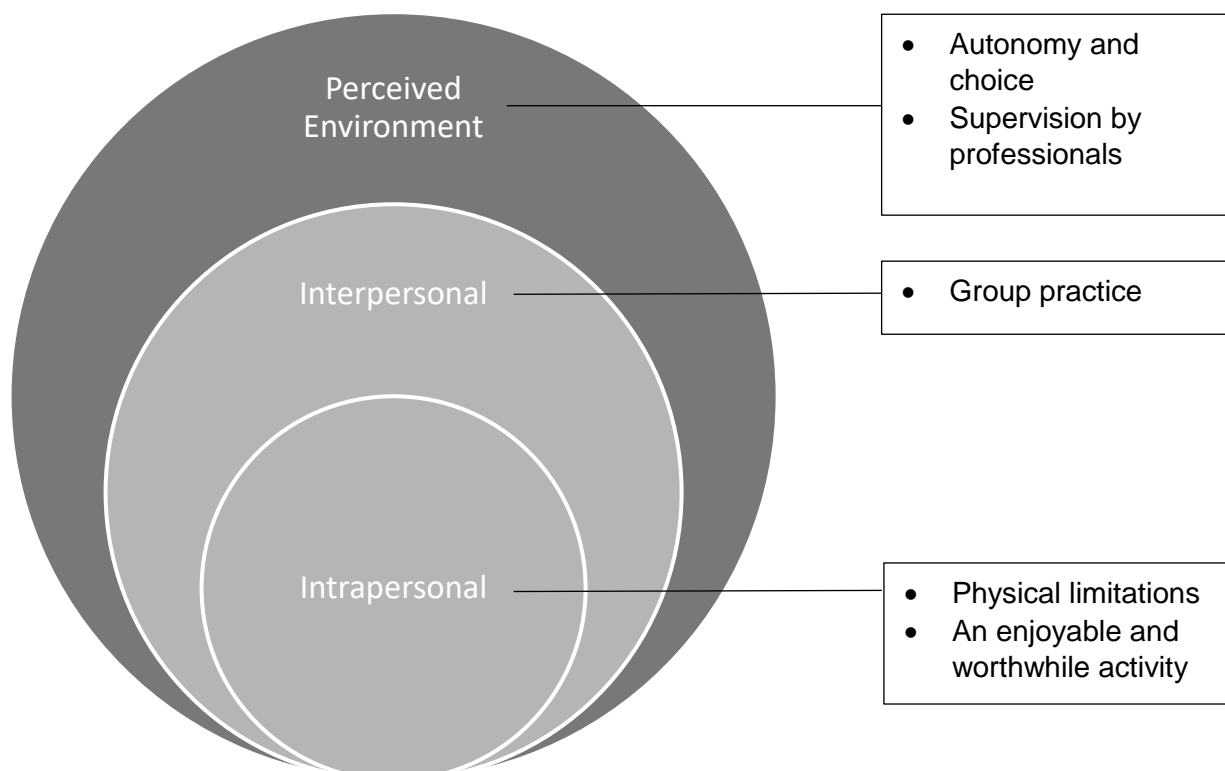

Figure 8: *Perceived barriers and facilitators to hospice-based Tai Chi at multiple levels of engagements*

9.1. Intrapersonal Level

Factors impacting participation in Tai Chi that fell within the intrapersonal level of the social ecological model related to characteristics pertaining to the individual. These included participants' attitudes, motivations, and beliefs towards Tai Chi, alongside the extent to which their disease-related physical limitations impacted their ability take part (McLeroy et al., 1988; Sallis et al., 2008). There were two factors that existed at this level which are represented by the sub-themes *physical limitations* and *an enjoyable and worthwhile activity.* These are described in the following section.

9.1.1. Physical limitations.

All participants in this study suffered from disease-related physical symptoms, co-morbidities, and de-conditioning which made some aspects of the Tai Chi (e.g., the physical movements) difficult to complete. These symptoms were reflective of the wider palliative population's physical experiences of advanced, incurable disease and included pain, muscle tensions, oedema, mobility, and breathlessness (LeMond & Allen, 2011; Seamark et al., 2007; Teunissen et al., 2007). In consequence, participants spoke about how disease progression created a sense of inhabiting a different, less capable body. This meant that although Tai Chi movements were calm and gentle, even the slightest exertion could be demanding, thus make some aspects of participation difficult. For example, Jane shared:

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

Thus, some movements (e.g., extending and abducting their arms and legs) were physically problematic for participants. This was because taking part in Tai Chi sometimes worsened already existing aches and pains in specific areas of their body (e.g., legs, shoulders, knees, and arms). Whilst experiences of pain were often

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temporary and subsided after movements had been reduced or stopped, for participants like Jane, the discomfort caused by pain lingered. This may have been a result of movements pushing participants' bodies beyond their physical limits thus causing peripheral nerve damage that increased the firing of inflammatory signalling molecules (Basbaum, Bautista, Scherrer, & Julius, 2009). This discomfort made taking part in certain movements unfeasible. For example, Debbie spoke:

> I used to do it [leg movements in Tai Chi] with me arm but I'm not sure that it's good for me shoulders that sometimes hurts, so now I only do the heel toe one with me hands and fingers. [interview 2].

Moving the body during Tai Chi, therefore, was not always a positive experience for participants. The discomfort caused by engaging in Tai Chi movements were visible in their facial expressions (e.g., frowning, scrunching, and grimacing) and body movements (e.g., shudders and grabbing/rubbing body parts). The following field note extract exemplifies this:

> As the physio instructed patients to lift and extend their leg gently as they imagined pushing a box forward, Leanne, who usually exerts herself more than her counterparts during Tai Chi sessions turned to Christie and told her: "I can't do this." Determined to nevertheless carry on she extended her leg once more which was met by the grimace of her face and a sort of whole body shudder. With pursed lips, she moved her hand and grabbed the top of her right leg. I turned and asked if she was ok to which her response made quite obvious that her hip was causing her a great deal of discomfort. [observational field note]

For some participants, pain and discomfort often acted as a barrier to full participation in Tai Chi. For others (particularly those with COPD and heart/lung disease), periods of dyspnoea caused through over-exertion undermined their ability to take part in the sessions. In many cases this triggered a vicious loop in which breathlessness stimulated feelings of anxiety which, in turn, further disrupted the breathing pattern of participants. The following observation and informal conversation with Shannon - a patient with pulmonary arterial hypertension and lung disease – demonstrates this process in action:

As I peered across the circle, I noticed Shannon was visibly out of breath and struggling to keep her upright posture. Her rosy red face made it quite evident that she had overexerted herself and pushed her body beyond its limits which meant that she had to sit out for the remainder of the session. After we had finished I took time to sit next to Shannon and check that she was ok after her breathless episode. As she rearranged the tubes that were supplying oxygen through her nose she turned to me and said:

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

Another disease-related physical limitation which acted as a barrier to taking part in Tai Chi was balance. For example, Debbie spoke about how because of the paralysis caused by spinal cord metastases, performing movements which required the steadying of her torso were often difficult:

it's the not the most physical thing I do cos I pull myself up my bed with my arms. I find it difficult to do anything because as soon as I, as soon I let go of here, or here [shows sides of wheelchair], I'm going to fall forward cos I've got no balance, so some of them [Tai Chi movements] I find hard. [interview 1]

The ways in which participants' disease-related physical limitations precluded participation in Tai Chi may be understood through how it interrupted the pleasant bodily rhythms that were associated with participation. Phoenix and Howe (2018) use the concept of interrupted embodied rhythms and apprehended motion as a novel way of thinking about how an individual's bodily capability may impede participation in physical activity. They draw on Edensor's (2013, p.167) notion of "somatic intrusions" (e.g., bodily discomfort caused by illness-related symptoms, physical de-conditioning and treatment side-effects) to demonstrate how sometimes "the unexpected and unwanted foregrounding of one's fleshy physicality [may

threaten] participants' quests for regular movement" (Phoenix & Bell, in press, p. not available). Indeed, this seemed to be the case in this study in that some of the Tai Chi movements unapologetically foregrounded participants' disease-related physical limitations (e.g., pain, fatigue, and de-conditioning) which reminded them of their inability to participate in sessions to the extent that they would have liked. These findings are, therefore, at odds with much of the literature which has neatly conformed to the "exercise is medicine" narrative. Within this narrative, studies have perpetually (and often uncritically) argued exclusively for the positive outcomes and accessibility of Tai Chi as an intervention in patients with a variety of advanced, progressive disease types (e.g., Cwiekala-Lewis et al., 2017; Hagglund et al., 2018; Leung et al., 2013; Polkley et al., 2018; Song et al., 2016; Vanderbyl et al., 2017; Wang et al., 2016; Yeh et al., 2013; Zhang et al., 2016). However, the findings above demonstrate that on occasions Tai Chi was an uncomfortable, unpleasant, and challenging experience which participants found difficult (Nesti, 2016).

An important note to bring attention to, however, is that whilst physical limitations did make taking part in Tai Chi difficult, it did not always preclude *complete participation* in sessions. This was because Tai Chi was a unique and multifaceted form of physical activity which included the potential to take part in movements, imagery, and music. Therefore, even in cases when physical movements were unviable, participants were still able to take part in and benefit from other aspects of Tai Chi sessions (e.g., listening to the soothing music and/or engaging in visualisations). For example, because she was paralysed from the hip down, it was literally impossible for Debbie to complete any of the leg movements of Tai Chi. However, she spoke about how during these parts of the sessions she often sat back and utilised the visualisation aspects of Tai Chi so that she could participate in the same routine as other participants but in different ways:

> obviously, it's difficult cos I can't do legs, but I don't feel left out cos I can't do legs, cos it just, I just as I say, 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]

Likewise, it was also common for Debbie to substitute and adapt movements that her paralysis made impossible. The following field note demonstrates how she

often overcame these difficulties through adjusting leg movements to her upper body:

> Until today, I had not noticed (or even thought about) how Debbie being wheelchair-bound due to paralysis from the hip down may impact her experiences of Tai Chi. When I watched her today, however, I recognised how in all of the moves that required movements of the legs, Debbie innovatively worked these into her own versions of arm movements. For example, when the physio guided patients through the movement that required them to imagine a puddle beneath their feet and to move their foot from the middle to the outside of the puddle, Debbie performed the movement with her hands. Similarly, this was replicated during one of the warm-up movements that requires patients to plantar flex and extend their feet. She proceeded to do so through flexing and extending her wrists. [observational field note]

Overall, participants' limited physical abilities often acted as a barrier to participation in Tai Chi. The stretching and reaching actions that Tai Chi encompassed could sometimes cause pain and discomfort meaning that some movements were uncomfortable and unfeasible. Whilst this did not preclude participating in the sessions in their entirety, it made full participation difficult.

9.1.2. An enjoyable and worthwhile activity.

For participants in this study, Tai Chi was generally viewed as an enjoyable activity which was an integral part of their overall hospice experience. For example, reflecting on how Tai Chi was a gratifying part of her day at the hospice Christie shared:

> I do quite look forward to the Tai Chi because I do enjoy it… I just perceive it as a whole, it's part of the whole experience of being here, the same as when I have my reiki treatment, that's part of the whole experience as well, it's all, all together, it's all part and parcel. [interview 1]

The predominant reason for participants' affection towards Tai Chi was the multiple benefits that they experienced through taking part. These were related to the various sensory and immersive pleasures that were covered under the sub-theme "pleasures of mind-body respite" in chapter 6, and "social engagements" in chapter

7. For example, Jane spoke about her fondness of Tai Chi and how she valued it as an activity in which she could experience pleasant sensory experiences such as relaxation and restfulness:

> I love [Tai Chi] ... it's so relaxing... when I've been here, I feel as different again when I go home, it's lovely, yeah. Yeah, I can really, I can really go with Tai Chi, I can … I can only describe it again, it comes back to the same, and that's peaceful. I could do with somebody doing it just before I go to bed, I wouldn't have any problems sleeping [laughs]. No, it is hard to describe, really hard. It's worth doing. [interview 2]

In these ways, Tai Chi was seen as a worthwhile and meaningful activity in which participants could be proactive in improving their well-being through taking practical steps to deal with disease-related issues. Doing something that could help them to (re)gain control over their health and well-being at a time in their lives where they often felt helpless and out of control was an important facilitator in taking part in Tai Chi sessions. Because of this, Tai Chi was a respected activity within the hospice setting. As Judy recalled: "it's [Tai Chi] respected … you notice people quietly sit and join in so it's, it is respected as a practical use otherwise people wouldn't do it" [interview 2].

Accordingly, these findings support Coveney and Bunton's (2003, p.163) assertion that: "pleasure might be considered a motive for human action (or indeed inaction) and is integral to understanding how humans interact with each other and their environment in ways that promote health." That is, because it was at once inherently enjoyable/pleasurable and pertained benefits that ameliorated their QOL, Tai Chi was simultaneously a source of intrinsic and well-internalised extrinsic motivation. Considering that Ryan and Deci (2007) present evidence demonstrating that, in some contexts, a combination of these types of motivation are more likely to facilitate prolonged engagement in physical activity as opposed to intrinsic motivation alone, this is an important finding with regards to patient adherence and maintenance of Tai Chi within palliative care contexts. Because participants enjoyed and valued Tai Chi as a way of being physically active, many commented on how they desired to do more as a means of maximising the benefits that they experienced through participation. For example, Roy spoke:

it [Tai Chi] were very limited to be honest, but I've done a lot of alternative stuff in, all through my life and I'd never done that, Tai Chi, ever. But although it were only limited and I didn't experience it for long, I thought it has the makings for being very good. It were very restful and it were very helpful all round … I should imagine if it were increased, you would find it even more beneficial… and I would imagine, also, if you did it more often, that that would lengthen the time afterwards, it [feeling relaxed] would increase, you know. [interview 1]

Echoing a similar sentiment that was shared amongst participants, Jane spoke about how she felt that Tai Chi was not conducted regularly enough in order to fully reap its potential benefits. She, like others, believed that if they were able to increase the frequency of times they took part per week, that they could magnify the benefits (especially those gained through the pleasures of mind-body respite) that they experienced:

I think, to be honest, the more you do it, the better it is. I mean, we come here and we do it once a week, and then our weeks are over and then we go home and start doing the normal things … I find the more I do them, the more I'm relaxed. But the thing is, you've got to keep it up you see, find the time for it … if you could do it every day I honestly think it would do you good … I think it would do you a lot of good because of the calming, it has a definite calming effect on both mental and physical. [interview 2]

In desiring to do more, some participants would have preferred to have engaged in Tai Chi multiple times a week. Likewise, other participants spoke about how they thought longer Tai Chi sessions would maximise the benefits they experienced. For example, Stan said:

Half an hour a week is nothing… I'd like to [do Tai Chi for longer than half an hour], to be honest … because I think it benefits. Particularly, I say it loosens up my joints and I think that's a good thing. [interview 1]

Whilst the majority of participants viewed Tai Chi as an enjoyable and worthwhile activity which they wished to engage in more often, caution should be taken in synonymising this with the idea that doing so would linearly enhance well-being. For example, Pat recognised that even if Tai Chi sessions were increased in

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frequency and/or duration, on its own, it would not be enough to solve her disease-related problems:

> The trouble is it doesn't last very long. It's no reflection on the Tai Chi, if you did a longer session of Tai Chi it would have benefits, but it would still not have the required benefits to bring me down as much as I need to come down. [interview 1]

9.2. Interpersonal Factors

Factors influencing participation in Tai Chi that were captured at the interpersonal level of the social ecological model related to how the informal socio-cultural networks and norms that were created between participants at the hospice acted as facilitators to engagement (McLeroy et al., 1988). This was represented by the theme of "group practice".

9.2.1. Group practice.

Participants spoke about how Tai Chi being conducted in a group setting was an important factor which facilitated their participation. Roy captured this when he told me that he saw Tai Chi as: "a group thing" [interview 1]. This is similar to much of the literature which has demonstrated the power of the group in exercise initiation and maintenance in patients with advanced and chronic diseases (Blaney et al., 2010; Clarke et al., 2015; Thorpe, Johnstone, & Kumar, 2012; Thorpe, Kumar, & Johnston, 2014). The ways in which the group was integral to participants' abilities and desires to participate in Tai Chi were multiple and complex. One role that it played was that - as described in length in chapter 7 - taking part in Tai Chi with other hospice patients fostered a sense of social connectedness and camaraderie. Accordingly, it made it a more pleasurable, enjoyable, and beneficial activity for participants, and in doing so, may have acted as a source of intrinsic motivation for engagement. For example, Judy recalled how the group dynamics of Tai Chi were enjoyable and helped her in reaching calm and meditative states:

> I think most things are more enjoyable when done as a group … I like the group dynamic. I like doing it [Tai Chi] in a group. I mean, it's only I find it very, very difficult to do at home on my own is meditate. To take myself out and zone everything else out and just go into that sort of quiet calm I find very,

very difficult if I'm on my own, if I'm in a group and were all doing it then I can do it. [interview 1]

Having the opportunity to share company around a common activity was an important facilitator in taking part in Tai Chi for participants in this study. Many participants emphasised the importance of the group as a source of motivation and encouragement to participate in Tai Chi through juxtaposing it with their experiences of attempting it at home on their own. For example, Pat expanded on how at home she struggled to initiate Tai Chi. The prospect of doing Tai Chi with others, however, was a source of encouragement which had the capacity to move her into action:

> I think that's a good idea [doing Tai Chi in a group] because at home before, they gave me a CD and they gave me instructions and I took one look and thought "mm, yes I'll do it sometime" and I don't even know where they've gone now. Where doing it in a group, somebody says its half past 12, it's time for Tai Chi: "come along and do Tai Chi," and you do... it's just like a family doing it together… it's a lot nicer. [interview 1]

Likewise, Jane recounted:

> when you're at home, you're doing other things and with Tai Chi you have to make yourself sit down and put the music on and go through the motions and that's the thing, you see, in life, you're doing other things, where here, you do it because you're in a group and you're sitting and you're doing it and the music's playing. At home, there's a tendency that these things get pushed away from you cos you're doing other things. [interview 1]

Comparisons with attempting to do Tai Chi at home highlighted how Tai Chi was "not the same on your own as with a group" [Gloria, interview 1]. This further demonstrates the importance of the socio-cultural context at the hospice in facilitating participants' engagement in Tai Chi. Participants' accounts suggest that the group facilitated their participation in Tai Chi due to the social cohesion that it created. This has been defined as: "a dynamic process which is reflected in the tendency for a group to stick together and remain united in the pursuit of its instrumental objectives and/or for the satisfaction of member affective needs" (Carron, Brawley, & Widmeyer, 1998 p. 213). Indeed, there is strong evidence to support that groups developing a strong sense of cohesion through working together

as communities enhances adherence behaviour in various types of physical activity (Burke, Carron, & Shapcott, 2008). Through forming synergies (Sebanz et al., 2006), therapeutic landscapes (Gesler, 1992), and giving and receiving support through engaging in the "craftwork" of illness (Frank, 2003) (as described in detail in chapter 7), participants were able to work together as a community towards the common goal of "feeling better". It is quite possible, therefore, that the social cohesion that was fostered as a result of this promoted participants' adherence and continued weekly engagement in Tai Chi sessions at the hospice.

What's more, many participants spoke about initially perceiving Tai Chi as "silly" and "daft"; something that they did not always feel comfortable taking part in. However, participating as part of a group helped to normalise an otherwise unusual way of doing physical activity thereby facilitating their enjoyment and likelihood to take part. For example, Stan recounted how the group helped him to normalise Tai Chi:

> once they were all doing it [Tai Chi] here, it just seemed natural. But until they were all doing it, you felt a bit odd and I felt odd the first time I tried to do it but then I got into it and quite enjoyed it.... You know, that first time we did it, it was odd and then I got into it and loosened up and when the others all did it as well, when the class did it, it was good... if everybody's doing it, you don't feel as though you're the odd one out. [interview 1]

In this way, Tai Chi appeared to be perceived by participants as somewhat of a "cultural norm" (Fetterman, 2010) within the day therapy unit of the hospice; an activity that was part of the day's routine that people *just did.* As demonstrated in Stan's quote above, over time Tai Chi was accepted and internalised by participants and in doing so made the activity appear ordinary – nothing spectacular, exotic, or unusual. This demonstrates the role that "enculturation" played at facilitating engagement in Tai Chi at the hospice (Griffin, 2017). That is, through prolonged, repeated exposure to Tai Chi and "mimesis" (i.e., copying what others within the cultural environment were doing), participants became encultured through embodying, and in a sense "buying into", Tai Chi as part of the day therapy unit's routine (Griffin, 2017). In facilitating participation, the acceptance of Tai Chi as a subcultural norm was important because as McLeroy et al. (1988, p.365) reminds us:

"the extent to which our interventions conflict with or support subcultural norms and values is the extent to which we can expect specific subgroups in the community to resist or support our approaches."

Overall, central to the enjoyment and subsequent facilitation of participants' engagement in Tai Chi sessions at the hospice was the importance of the group setting. Participants felt that engaging in Tai Chi with others made for a more pleasurable and beneficial experience. Others' participation in Tai Chi also acted as a source of encouragement to take part in sessions and helped to normalise an unfamiliar method of physical activity.

9.3. Environmental/Community Level

Critical reflection 10: Capturing culture at work

During data collection it soon became apparent that the environment in which Tai Chi was conducted was important with regards to the factors that facilitated participation. A note from my reflexive journal exemplifies this:

> "A pattern that I have noticed, which is more to do with the culture at the hospice, is the way in which Tai Chi is conducted fits in with the patient-centred ethos of the hospice more generally. Patients are not obliged to take part, they only do so if they want to. Even within the session patients are continually reminded to only push themselves as far as they feel comfortable. Everything that is done during Tai Chi and in the hospice in general is very much down to the patient's discretion. I feel as though these are examples of culture at work and positively impact the ways in which participants feel they are able to take part in sessions."

As I engaged in data analysis that moved up the socio-ecological model (e.g., to the perceived environment level) I was particularly attentive in trying to contextualise findings through using the type of 'thick description' that Geertz (1973) talks about. That is, rather than simply describing the facilitators experienced by participants, to expand on these through explaining how they were embedded within, and affected by, the cultural milieu of the day therapy unit.

Factors that fell within the perceived environment level of engagement move away from neoliberal discourses pertaining to the intra- and inter-personal processes that affected participants' engagement in Tai Chi. It does so through taking a broader approach which considers how the cultural environment and atmosphere in which Tai Chi sessions were conducted impacted participation. There were two factors that existed at this level which facilitated participation in Tai Chi which are demonstrated through the subthemes of: *autonomy and choice* and *supervision by professionals*

9.3.1. Autonomy and choice.

Ekkekakis (2009) and Ekkekakis, Parfitt, and Petruzzello (2011) argue that performing physical activity at self-selected, instead of prescribed and imposed levels, is more likely to aid its initiation and maintenance. Indeed, in this study, participants commented on how experiencing a sense of autonomy and choice to adapt movements in ways that allowed them to tailor sessions to their personal needs and physical abilities was important in facilitating their participation in Tai Chi. This was captured through the notion of "doing what one could", a common phrase used amongst participants which highlighted the salience of being in control of how they decided to take part in Tai Chi. Having the autonomy to do what one could was a tacit rule that underpinned sessions and represented the ethos of the hospice more generally. That is, the patient-centred values of the hospice culture - in which patients were put at the centre of every decision that was made regarding their health and well-being (see chapter 5.2) - naturally seeped its way into the sub-culture of Tai Chi sessions. Debbie spoke about how the implicit rule of doing what one could governed Tai Chi sessions during an interview:

AB: Do you feel that there are any kind of rules that guide the session?

D: I think the rules are good, just do what you can and if you can't, stop and I think it's good for everyone, you know, cos even [patient's name] who don't join in the movements, you know, he listens to the music and watches and it relaxes him. So, that's what I think that at the beginning of the session, were allowed to be who, as we are, you know ... so I think, in a way, probably no rules, cos the rule is, do what you can, you know, or do what you feel; if it's not right for you, don't do it. [interview 2]

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Whilst "doing what one could" meant different things to different participants it epitomised the way in which they were able to cognitively "frame" their Tai Chi experiences in self-determined ways (Ekkekakis et al., 2011). That is, it was not seen as something that they felt they *must do,* rather, it was something that they felt they could *choose* to do (Ekkekakis et al., 2011). More often than not, this reflected how participants pragmatically adapted Tai Chi in ways that aligned with their physical abilities/needs. For example, participants commonly omitted movements that they found difficult due to pain or functional limitations (e.g., poor balance, reduced strength, breathlessness, paralysis etc.), and instead focused on completing movements that they were physically capable of. For example, Stan spoke:

> there's some weeks when my feet and legs feel so heavy that I just can't lift them, so then I just do the arm movements… It's [the Tai Chi] not compelling, you know, you don't have to feel "ooh, you know I'm failing, cos I'm not doing it," you know, you just get on with what you can do and that's all part of the fun. [interview 1]

Being able to adjust movements that they found uncomfortable without feeling judged by others was important in facilitating participation, particularly because it helped overcome some of the barriers to taking part that were covered in the sub-theme of "physical limitations". Therefore, the implicit notion of "doing what one could" that ran throughout sessions made Tai Chi a non-compelling, inclusive activity in which patients were able to tune in and listen to their bodies. In the words of Judy, it meant that: "everybody can join in, whatever level they're at" [interview 1]. Whilst for some participants autonomy and choice was about omitting movements that were unfeasible or painful, for others, it was about being able to alter the range of movements in ways that matched the limits of their body. For example, Debbie recounted:

> you can do what you need, you know, like when she says "fly with your arms" you can just go like that with your hands [flaps her hands close to her side] you know and you don't have to do big movements and I like how they re-iterate "stop if you need to," you know, that kind of thing. [interview 1]

Indeed, the following field note illustrates how participants modified the range of Tai Chi movements to suit their body's capabilities:

As the session was nearing its mid-point participants were adducting and abducting their arms and fingers as they imagined they were doves flapping their wings on a bright, blue summer's day. As I looked across the room I noticed that participants were engaging in the movement to varied extents. As he imagined flapping his imaginary wings, careful not to hit the person next to him, Roy spread his arms into what appeared to be their maximum wingspan and then gently brought them back to the middle of his chest. Lee, however, was a lot more conservative in his approach. His elbows were tucked in to his torso as he carefully moved his forearms only slightly outwards and then back in again. [observational field note]

Feeling as though the range of movements could be tailored to the capabilities of one's body was important in making Tai Chi a more enjoyable and accessible activity. Furthermore, for some participants, being able to adapt and tailor movements to their needs and abilities was about being able to complete them at their own pace and within their own time without feeling as though they were doing it "wrong":

I don't always keep up with it, I'm a bit, co-ordination's not brilliant, but I don't allow that to worry me. One time, I would, if I was doing it I would have to be doing it perfect or I wouldn't be happy, now I don't care. I do what I can, if my rhythm's not quite right and my hand's going that way and my eyes going this way, I don't get banged up in it, I just do it at my own pace. [Judy, interview 1]

Overall, key to facilitating participants' engagement and enjoyment in Tai Chi sessions at the hospice was the freedom that they experienced in relation to tailoring different movements so that they matched their physical needs and capabilities. This was captured in the notion of "doing what one could" which represented the non-compelling culture in which Tai Chi was conducted. This meant that participants felt able to omit certain movements, complete them at their own pace, and/or modify their range and intensity without feeling as though they were doing it "incorrect".

9.3.2. Supervision by professionals.

Similar to other findings within the advanced disease and exercise literature (e.g., Blaney et al., 2010; Clarke et al., 2015; Gulde et al., 2011; Kartolo, Cheng, & Petrella, 2016; Paltiel et al., 2009; Turner et al., 2016), participants in this study

spoke about the importance of professional supervision in facilitating their participation in Tai Chi. The need for guidance and support was particularly important considering that many patients expressed a lack of confidence in being physically active because they were unsure of how far they could and should push their bodies. This falls in line with other studies in this area which have highlighted how physical de-conditioning and impairments (e.g., reductions in mobility, breathlessness, fatigue, and lack of balance) often undermine palliative patients' confidence in moving their bodies without supervision or advice (Blaney et al., 2010; Clarke et al., 2015; Mulligan, Hale, Whitehead, & Baxter, 2012). Furthermore, because Tai Chi was only delivered at the hospice once a week, participants felt as though the physiotherapists were needed to guide them visually and verbally through the movements and imagery of Tai Chi routines. For example, Debbie told:

> I think the [physio's] voice at the moment is important because …we do it [Tai Chi] once a week, with other things going on … we never do the same. You know, the half hour, some people [physios] begin with different exercises, so it's not something, it's not a routine you can learn, cos it's disjointed in that way, cos it's done by different people. So I think the [physio's] voice is important to listen to, to know what movement you're doing next really. [interview 2]

Therefore, in line with self-efficacy theory (Bandura, 1977) the guidance, support, and reassurance provided by the physios at the day therapy unit seemed to enhance participants' confidence in their ability to engage meaningfully in Tai Chi sessions. Another way in which physiotherapists facilitated participants' engagement in Tai Chi was through how their enthusiasm contributed to a positive and fun environment. This was something that seemed to rub off on participants, thus making them more inclined to engage in sessions. Christie compared her experiences of doing Tai Chi at home with doing it at the hospice to emphasise the motivational role that the physio's played in making Tai Chi easy and fun to take part in:

> The key differences [between doing Tai Chi at the hospice and home] are the timing and the fact that somebody's [the physio's] directing you rather than at home, I would be saying "ooh, I'll do it later, I'll do it later," "it's too late, I'll do it

tomorrow, I'll do it tomorrow" until it never gets done at all. Where here, you see: "it's time for tai chi", and it's made a positive experience "come on, who's joining in," you know. A bit like you would, this is not mean to be patronising, but a bit like you would with kids, you know: "here, come on, it's time to join in, time for story". [interview 1]

As well as facilitating participation in Tai Chi by guiding and motivating participants, the physiotherapists also played an integral role in creating a pressure-free and non-judgmental culture in which participants felt that they could be themselves and freely tailor moves to suit their own capabilities. The prominence of having the autonomy and choice to tailor movements was demonstrated in the previous sub-theme. For example, Judy highlighted the importance of the physiotherapists in cultivating a respectful and caring environment in which participants could be themselves, through comparing her experiences of Tai Chi at the day therapy unit with experiences she had of doing physical activity in other settings:

they [the physios] don't put any undue pressure on you. I decided some years ago that I'd try yoga and I went to the local sports centre and joined a yoga class and I felt as if I was under pressure all the time, he said: "only do what you can" but the minute you stopped: "why have you stopped?'". They don't do that [here] they say and they mean it. If you can't lift your arm above your head, don't lift your arm above your head. If you can't sit forward, sit back and they mean it. They're not, there's no pressure on any of us to perform… you're not pushed too far... they're not saying: "you've got to sit up straight" you can do it in the way that fits in with you and there again, it's all back down to this mutual respect and caring … it makes me look forward to it, whereas if there was sort of rigidly laid down rules, I'd probably go and sit in the corner with a book or whatever, I wouldn't take part in it. So I do look forward to it. [interview 1]

The culture that the physiotherapists helped to cultivate, therefore, was integral in facilitating participants' engagement in Tai Chi sessions and highlighted the uniqueness of the hospice as a cultural setting in which it was conducted. During my time in the field, it soon became obvious that the physiotherapists leading Tai Chi

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sessions went to great lengths in saying and doing things which explicitly endeavoured to create a non-compelling and patient-centred atmosphere. For example, the following field note exemplifies the way in which physiotherapists would take time at the start of each Tai Chi session to remind participants to only complete movements at a level that they felt comfortable with:

As the physio sat at the head of the circle she took a moment to encourage participants to only push their bodies to a point that felt right saying:

"Everyone must remember the Number 1 rule: don't overexert or push the body to points where it is uncomfortable. So for example, if we're doing leg movements like stepping over the pond and it hurts doing this [exaggerated her leg extending in front of her body as she mimicked it stepping over a pond] then perhaps its best if you make a smaller movement that doesn't hurt, or perhaps stop and just complete the movements that you can". [observational field note]

The sentiment of not over-exerting or pushing oneself to uncomfortable levels was one that (when necessary) physiotherapists revisited and reaffirmed throughout sessions. For example, when it was obvious that certain participants were struggling with movements, they gave gentle reminders of not pushing through pain. These reminders were accompanied by the offering of practical advice of what participants could (not should) do to make taking part easier. The following field note extract exemplified this in action:

During the tree movements, it was quite obvious to see that Jane was in some pain. Her face was scrunched as she reached her right hand up and placed it over her right shoulder. She made a gesture to the physio that she was experiencing some discomfort because of the movements. The physio's running the session realised this and gently reminded Jane that she was not to put herself through any pain and suggested that she may want to not raise her arms as high on their ascent, or perhaps to only use one arm to complete the movement. Based on this advice, initially, Jane started to decrease the length through which she lifted her arms up. As this was still causing her considerable amounts of pain, I noticed how she then proceeded in

completing further Tai Chi movements with only her right arm. [observational field note]

In these ways, the physiotherapists' approach to delivering Tai Chi was differentiated. This concept refers to a scepticism of delivering Tai Chi in standardised ways and, instead, challenging "all learners by providing materials and tasks on the standard at varied levels of difficulty, with varying degrees of scaffolding, through multiple instructional groups, and with time variations" (Tomlinson, 2000, p.4). Thus, the examples given above demonstrate how physiotherapists were able to open up (i.e., make more accessible) Tai Chi sessions through providing participants with the opportunity to take part in Tai Chi at intensities, speeds, and levels which they felt comfortable with. As well as facilitating participation through making Tai Chi sessions more accessible, it also meant that participants could benefit from Tai Chi in different ways. In the words of Roy:

> some people benefit more than others and benefit in different ways. So as I say, they benefit physically, some benefit mentally, some benefit spiritually. But however they benefit, it aint doing any harm, its benefitting ... if you pick up on all three, better still, but if you just pick up on one of them and it just gets your arms and legs moving about a bit better. [interview 1]

Overall, participants spoke about how the physiotherapists leading the sessions at the hospice were essential in making them more likely to participate in Tai Chi. They did this through fostering a positive and pressure-free environment in which they encouraged and guided participants through Tai Chi in ways that made it more accessible, enjoyable, and effective.

9.4. Summary

In this chapter I described participants' views on, and the perceived barriers and facilitators that they faced in relation to, participating in a hospice-based Tai Chi program. I did so through utilising conventional realist tales to tell the reader how factors residing at multiple levels of the social ecological model (e.g., intrapersonal, interpersonal, and perceived environmental) impacted engagement in positive and negative ways. Factors at each level interacted, often in reciprocal ways. For example, group practice (i.e., at the interpersonal level) was integral in contributing

towards Tai Chi being perceived as an enjoyable and worthwhile activity (i.e., at the intrapersonal level) and vice versa. Based on this model, I underscored the importance of hospice-based Tai Chi being a group-based activity which is delivered by trained staff and provides tailored support that encourages autonomy and enjoyment. These findings also demonstrate the need to be vigilant of how patients' disease-related physical limitations may make participation in Tai Chi (and other, similar physical activity interventions) unpleasant and challenging. The data from this chapter, therefore, has various practical implications (covered in chapter 10.2) with regards to how we may seek to design and implement Tai Chi interventions within hospice contexts.

Part 3

Closing.

Chapter 10: Implications and Conclusions

10.0. Overview

The final chapter now seeks to bring this thesis to a close through drawing together the findings presented between chapters 6-9 and discussing their empirical implications. Based on these, I then offer various practical recommendations that may be helpful to health professionals, academics, and patients who seek to utilise Tai Chi as a means of improving QOL. Furthermore, I also use this section to reflect on the various methodological techniques used in this study, alongside its limitations and possibilities for future research.

10.1. Empirical Implications

This is the first empirical study of its kind to adopt an ethnographic approach to explore advanced, incurable disease patients' views and experiences of participating in a hospice-based Tai Chi program. In doing so, the findings presented within chapters 6 to 9 of this thesis add novel understanding to the ways through which we may understand how Tai Chi, and physical activity more generally, may improve the QOL of terminally ill patients within the context of hospice day care. The empirical contributions of each chapter are addressed in the following sections.

10.1.1. Hospice-based Tai Chi and QOL: The Craftwork of Illness.

Through adopting an ethnographic approach, the findings presented between chapters 6 and 8 provide a thoroughly situated account of participants' experiences of Tai Chi and QOL within the context of hospice day care. In doing so, this is the first study of its kind which acts on the calls of various scholars (e.g., Li et al., 2014; Wang et al., 2010; Yeh et al., 2004) to utilise purely qualitative methodologies to explore the mechanisms through *how* Tai Chi was able to improve QOL in patients with advanced, incurable disease. This is important because:

> knowledge about the physiological and psychological effects of Tai Chi exercise may lead to new complementary and alternative medical approaches to promote health, treat chronic medical conditions, better inform clinical decisions and further explicate the mechanisms of successful mind-body medicine. (Wang et al., 2010, p.14)

Through achieving this, the findings of this thesis have numerous valuable empirical contributions to the literature. These may be best understood through appreciating the ways that Tai Chi seemed to be an activity in which participants - who suffered from a range of advanced and chronic diseases - could engage in what Frank (2003) calls the "craftwork of illness". This was through how they appeared to use it as a way to view their lives in more enjoyable, pleasurable, and socially connected ways.

Chapter 6 demonstrated one way in which participants were able to engage in this craftwork of illness. That is, participating in hospice-based Tai Chi was able to enhance participants' perceptions of their QOL through allowing them to experience their minds and bodies in pleasurable ways. In doing so, this study consolidates findings from systematic reviews and randomised control trials which have demonstrated the efficacy of Tai Chi at improving overall QOL and relieving distress related to the body (e.g., fatigue and treatment side-effects) and mind (e.g., worry, anxiety, depression) in patients with a range of advanced and chronic diseases (e.g., Chuang et al., 2017; Huang et al., 2016; Oh et al., 2010, 2012; Song et al., 2017; Vanderbyl et al., 2017; Wang et al., 2016).

However, this study also extends these findings through offering explanations of *how* Tai Chi was able to achieve improvements in participants' QOL. In particular, they underscored the importance of the various facets of Tai Chi (e.g., gentle movements, soothing music, and visualisations of nature) in culminating in a variety of sensory and immersive pleasures that were located in the mind (i.e., being present in the moment) and body (i.e., a sense of embodied peace) of participants. These pleasures were inter-connected and interacted in mutually reciprocal ways that provided participants with a portal to the present moment in which they could experience a serenity of their whole being through gaining respite from their illness. Accordingly, this project provides a unique perspective on the role that pleasure plays during Tai Chi experiences in patients with terminal illness, something that Phoenix and Orr (2014, p.101) have labelled as a "forgotten dimension of physical activity". Specifically, through allowing participants to experience their minds and bodies in pleasurable ways, Tai Chi acted as a form of "embodied learning" (Griffin, 2017) in which they were able to (re)learn how to connect with their minds and bodies in comforting and peaceful (as opposed to chaotic and distressing) ways.

This demonstrates how participants used Tai Chi to "craft" a new relationship between their mind and bodies, something that is particularly important given that experiences of pain, anxiety, and depression are common in patients with advanced, incurable disease and drastically increase the likelihood of them desiring a hastened death (Breitbart et al., 2000).

Furthermore, most research that has explored the impact of Tai Chi on QOL in palliative populations has focused on physical and psychological outcomes through utilising research designs such as randomised controlled trials, pre-post-tests, and quasi-experimental studies (e.g., Cwiekala-Lewis et al., 2017; Hui, Cheng, Cheng, & Lo, 2008; Li et al., 2014; Song et al., 2017; Zeng, Luo, Xie, Huang, & Cheng, 2014). Consequently, understandings of the social, cultural, and relational processes of Tai Chi have been pushed aside, thus presenting a very narrow view of what taking part in hospice-based Tai Chi can mean to patients in this context (Nicholls, Jachyra, Gibson, Fusco, & Setchell, 2018; Williams et al., 2017). Thus, the empirical findings presented in chapter 7 provide unique insight into the importance of social engagements during Tai Chi sessions in improving participants' perceptions of their QOL. Because Tai Chi brought participants together and provided an activity in which they could meaningfully connect with other patients who had a shared understanding of terminal illness, it helped to alleviate feelings of social and emotional isolation. This finding resonates with other research which has demonstrated the positive role that group exercise settings in general can play at improving QOL in patients with advanced and progressive diseases (e.g., Adamsen et al., 2012; Gulde et al., 2011; Hogg et al., 2012; Malcolm et al., 2016; Paltiel et al., 2009; Turner et al., 2016). These have used various qualitative designs including explorative, grounded theory, and phenomenology. However, by using the ethnographic approach, this study also extends our understandings of how social engagements may manifest into improved QOL in this population. Through immersing myself in the field over a prolonged period of time I was able to observe how participants used Tai Chi at the hospice as a platform through which they could further engage in the craftwork of illness. This was demonstrated through the ways in which they embodied a collective identity where they used understandings of their own vulnerabilities to reach out and support other patients who were suffering in similar ways. This represented a form a "relational resilience" in which Tai Chi

provided an activity that participants used to work together in coping with the traumas of their illness (Jordan & Harding, 2002).

Another novel empirical contribution of this project (and one that was also afforded through the use of an ethnography) is that it underscores the importance of the hospice as a socio-cultural context in which the aforementioned benefits of Tai Chi were situated. That is, integral to participants' experiences of mind-body respite and social engagements were the ways in which the hospice day therapy unit provided a unique "affective environment" (Andrews et al., 2014) and "therapeutic landscape" (Gesler, 1992) in which Tai Chi was conducted. These represented the environmental features (e.g., calm music, soothing ambiences, and a supportive/healing atmosphere) as well as the tacit rules and routines present within the day therapy unit that were crucial in contributing to participants' positive experiences of Tai Chi. Accordingly, simply taking part in the activity of Tai Chi was not enough in fostering the benefits that were experienced through the pleasures of mind-body respite or social engagements. Indeed, many participants commented on how doing Tai Chi in different environments (e.g., at home) did not have the same benefits as it did at the hospice. Rather, the day therapy unit in which Tai Chi was conducted comprised of a number of therapeutic "opportunity structures" – or "basic functions" (Andrews et al., 2014) - that pertained the capacity to act on participants in ways that were beneficial to their QOL in ways that other contexts did/could not. From this perspective, therefore, improvements in QOL that were experienced through taking part in Tai Chi were just as much a product of participants' connections with the physical and socio-cultural environment that was created during sessions as it was an internal experience. These findings, therefore, contribute to the literature in novel and insightful ways through demonstrating the interpersonal and cultural processes that were integral to participants' experiences of Tai Chi and QOL within the hospice setting.

This study also contributes new knowledge to this area through demonstrating the potentially negative and messy ways through which patients with advanced and progressive diseases may experience Tai Chi. Almost all research in this area has focused solely on the benefits of physical activity on well-being across a multitude of diagnoses that comprise the palliative care population (e.g., Albrecht & Taylor, Lowe et al., 2009b; McCarthy et al., 2015; Pedersen and Saltin, 2015, Turner et al., 2016)

and this is a trend that is reflected in work that explores the impact of Tai Chi on QOL (e.g., Cwiekala-Lewis et al., 2017; Hui et al., 2008; Li et al, 2014; Song et al., 2017; Zeng et al., 2014). However, if we are to gain an accurate and rounded understanding of how patients experience Tai Chi (and other physical activity interventions) in palliative care settings, thus inform health professionals in meaningful and useful ways, it is crucial that the potential negatives, difficulties, and challenges of participation are not neglected or brushed over. Thus, the empirical findings presented in chapter 8 add fresh insight into the ways that Tai Chi may be experienced by this population. That is, whilst for the majority of participants in this study Tai Chi was a positive experience that improved their QOL, this was not the case for all. Some participants simply found no benefit through taking part and experienced Tai Chi as boring and lacklustre. Furthermore, even for some participants who did benefit, there was a feeling that because it was somewhat of an unusual activity, Tai Chi was a complex art that had to be mastered. This entailed repeatedly engaging in sessions so that they could learn the "body techniques" and "corporeal schemas" (Griffin, 2017; Mauss, 1973) that were necessary in order for them to experience benefits such as the pleasures of mind-body respite. These findings, therefore, present alternative meanings that Tai Chi may take on for patients with terminal illnesses.

10.1.2. Views, Barriers, and Facilitators to Hospice-Based Tai Chi.

This is also the first empirical study of its kind to utilise a social ecological model as an overarching framework to explore palliative patients' perceptions of, and the barriers and facilitators that they experienced in relation to, participating in a hospice-based Tai Chi program. It demonstrated how the barriers and facilitators to taking part in Tai Chi consisted of a complex interplay of factors that fell at multiple levels of engagement. These included intrapersonal (e.g., an enjoyable and worthwhile activity and physical limitations), interpersonal (e.g., group practice), and environmental (e.g., autonomy and choice and supervision by professionals) levels of influence. Factors at each level of engagement interacted in multi-directional ways. For example, an encouraging and supportive social environment facilitated participation in those who had physical health concerns. This study supports findings from a small yet growing body of research that have explored the barriers and facilitators that exist for advanced and chronic disease patients who are enthusiastic

about participating in physical activity (e.g., Blaney et al. 2010; Clarke et al., 2015; Elsworth et al., 2009; Thorpe et al., 2012; Thorpe et al., 2014). These have demonstrated that common barriers to participation include health status (e.g., symptoms, co-morbidities, and treatment side-effects) and program specific barriers (e.g., negative prior experiences of physical activity and lack of support). Facilitators were often the inverse of barriers and included physical activity interventions being tailored, guided by professionals, offering social support, and the prospect of improving health.

Through adopting a focused ethnography, the findings of this study also adds to this literature by responding to the calls of leading researchers in the area of public health (e.g., Das & Horton, 2012; Hallal et al., 2012; Heath et al., 2012; Kelly & Barker, 2016) in recognising the physical, social, and cultural environments that may facilitate or preclude participation in physical activity within a hospice context. That is, it demonstrated how the complex physical activity needs of patients with advanced, incurable disease were located within the specific cultural context of hospice day therapy. For example, they underscore the importance of Tai Chi – and physical activity more generally - being conducted in patient-centred cultural settings that encourage autonomy and choice, and how physios play an integral part in cultivating these environments. Accordingly, this study highlights the uniqueness of the hospice setting in targeting potential mechanisms in promoting the uptake and maintenance of Tai Chi (and other physical activity) interventions within this population. This knowledge provides the foundation on which interventions can be made at various levels of the social ecological model to enhance the effectiveness and accessibility of physical activity within hospice settings. Designing multi-level interventions is of particular salience bearing in mind that these types of interventions (as opposed to those that target single levels) are more likely to result in positive behaviour change and health promotion (Boulton et al., 2018; McLeroy et al., 1988; Sallis et al., 2008).

Collectively, the empirical lessons learned from this study can be used to better design and implement physical activity interventions within hospice contexts. This is by creating programs that are centred on aspects of physical activity that patients find easy, enjoy, and benefit from, whilst addressing and limiting those that prevent participation. The practical implications section goes further in expanding on

how these empirical findings were used to make evidence-based recommendations at various levels of the social ecological model as a means to achieve this.

10.2. Practical Implications and Recommendations

Based on the above, there are a multitude of practical implications arising from this project that may be used by health-care professionals, academics, patients, hospices, and other relevant parties who are interested in bettering palliative care practice. The following practical recommendations are offered as key "take-home messages" that may be used by healthcare professionals working in palliative care (e.g., doctors, nurses, physio/occupational therapists etc.) and patients as a means to improve QOL in the context of advanced and chronic disease. In making recommendations spanning macro, meso, and micro levels of the social-ecological model, these findings form the basis of addressing the "translational gap" (Ferlie, Crilly, Jashapara, & Peckham, 2012; Woolf, 2008) between knowledge produced through doing research and clinical practice.

Take home messages for health-care professionals:

- ***Tuning in with patients' embodied rhythms.*** In developing interventions that are effective at improving QOL, it is necessary for health-care professionals working in this setting to understand how patients' perceptions of time may impact their overall disease experiences (Ellingsen et al., 2012; Giuliani et al., 2015). One way of achieving this is for health-care professionals to utilise interventions and techniques that are able to "tune in with the other's embodied rhythm" (Ellingsen et al., 2013 p.171). This includes being responsive to how physical suffering (e.g., pain, fatigue, nausea etc.) can "trap" patients in embodied time, dictating the paces and places through which they can function. It also means being vigilant to how functioning in embodied time (e.g., time dictated by the body) often precludes patients feeling as though they can participate in a world which is governed by clock time (e.g., time dictated by hours, minutes, and seconds) and how this can cause feelings of isolation and estrangement. In doing so, we may work towards maintaining patient dignity and delivering better quality care during the final stages of their lives. Tai Chi presents one such intervention which may be able to

achieve this.

- **The importance of respite.** In certain instances – particularly when disease-related issues are irresolvable – healthcare professionals may seek to improve patients' QOL through utilising interventions that focus on allowing patients to enter modes of "being" (e.g., appreciating their minds and bodies in the present moment) as opposed to "doing" (e.g., active problem solving) (Dimidijan et al., 2010). This may provide patients with much-welcomed/needed respite from thinking about, and being consumed by, the physical, psychosocial, and existential issues that their disease poses.

- **The value of Tai Chi.** In working towards the above, Tai Chi may be used not only as an adjunct to pharmacological treatments but as an integral aspect of rehabilitative palliative care in addressing the multifaceted and complex health needs of terminally ill patients, regardless of disease type. In particular, mindful movement therapies are able to work towards calls for high quality rehabilitative palliative care (e.g., Hospice UK, 2015; National Palliative and End of Life Care Partnership, 2015) which empowers active living and allows patients to function "as independently and fully as possible … and cope constructively with losses resulting from deteriorating health" (Hospice UK, 2015, p.2). Therefore, they should be should be taken seriously as a treatment option by health-care professionals seeking to better the lives of patients with advanced, incurable disease through being integrated into the multi-disciplinary and holistic approach which is central to palliative care.

- **Design, implementation, and delivery.** Based on the empirical findings presented between chapters 6-9, there are numerous practical recommendations that can be made at various levels of the social-ecological model with regards to how health-care professionals may design, deliver, and implement Tai Chi (and other physical activity) interventions within a palliative care context. Accordingly, they aim to improve the effectiveness and accessibility of these types of therapies

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within hospice contexts for patients with advanced, incurable diseases. Whilst the following relates to recommendations for future Tai Chi programs, these findings are applicable to hospice-based physical activity and mindful movement therapies more generally:

- *Community Level.* Within local communities, hospices should be seen as "targets" and "diffusers" (McLeroy et al., 1988) of mindful movement therapies (and other physical activity interventions) for patients with advanced and chronic diseases. This is because they represent one of the few places in the community that have the resources needed for patients to feel safe and confident in engaging in physical activity and exploring their body's capabilities.

- *Environmental Level.* Interventions should be supervised by qualified and trained health-care professionals who are able to guide, motivate, and support patients before, during, and after their participation. It is also important for healthcare professionals leading the sessions to recognise that there is no "one size fits all" (Williams et al., 2017) approach to delivering Tai Chi to patients with a variety of advanced, incurable diseases. Thus, the delivery of Tai Chi and physical activity interventions in this context should be centred on the ethos of "differentiation" (Tomlinson, 2000) and conducted in cultural environments which support patient autonomy and choice. This is important in ensuring that these types of interventions are able to be tailored to the wide range of diagnoses, needs, and abilities of patients who will be partaking in sessions. Furthermore, in order to facilitate the benefits to participation that are discussed in detail in chapters 6 and 7, Tai Chi sessions should be conducted in carefully crafted affective environments (e.g., calm, quiet, and soothing places) and therapeutic landscapes (e.g., spaces which provide the opportunity for

patients to connect with others and work together in mutually healing ways to cope with their illnesses).

- *Interpersonal Level.* Tai Chi sessions should be group-based, ideally with other patients who have a shared understanding of what it means to live with terminal illness. These types of groups present the potential for patients to feel connected to a community who they can work with in coping with their illness. They also pertain the power to motivate patients into initiating and adhering to Tai Chi interventions through creating a fun and encouraging environment.

- *Intrapersonal Level.* Tai Chi sessions should be centred on fun, enjoyment, and pleasure as well pertaining recognisable instrumental value (i.e., participants are able to identify the ways through which taking part may contribute to being proactive in dealing with their illness). However, health-care professionals should remain vigilant and responsive with regards to how patients' disease-related physical limitations (e.g., pain, fatigue, breathlessness, oedema etc.) may make participation a potentially unpleasant and challenging experience.

Take home messages for patients:

- Whilst living with advanced, incurable and chronic diseases can at times be chaotic, stressful, and uncomfortable, mindful movement therapies (such as Tai Chi) represent a safe and feasible method of physical activity that may be used to improve QOL.

- Hospice-based Tai Chi is a form of physical activity which integrates the mind and body and has the potential to address various illness-related issues that you may experience. These include:
  - Physical problems (e.g., pain, fatigue, breathlessness, muscle tensions) through allowing you to experience your body in peaceful,

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relaxed, and restful ways.

- o Psychological suffering (e.g., anxiety, worry, and depression) through providing a mentally relaxing activity that helps you to take time-out from your illness.

- o Social and emotional isolation through allowing you to connect with other patients who have a shared understanding of illness and work together in a fun and calm atmosphere in being proactive in dealing with your disease.

10.3. Methodological Reflections

This thesis also has various methodological implications that contribute to the field of qualitative research in exercise, health, and palliative care. Firstly, it progresses our methodological understandings with regards to how the focused ethnographic approach (Knoblauch, 2005; Wall, 2015) can be utilised effectively within palliative care settings. To my knowledge, with the exception of Williams-Reade et al.'s (2015) work on issues surrounding the implementation of a neonatal palliative care program, this type of methodology has not been utilised in this context. Its potential value, therefore, has been underexplored.

Utilising a focused ethnography granted me the opportunity to immerse myself in the day therapy unit of the hospice over prolonged periods of time (i.e., 8 months) whilst utilising multiple, complementary forms of data collection. Through doing this, I was able to develop an intimate and rich understanding of the cultural context of the day therapy unit that otherwise would not have been accessible. This was invaluable in providing a contextual/cultural backdrop through which the findings presented in chapters 5-9 could be enriched, and in doing so, led to a unique insight which underscored the importance of the hospice setting with regards to participants' views and experiences of Tai Chi. For example, it illuminated the nuances of Tai Chi as a sub-cultural activity within the broader social context of the hospice through demonstrating how the unique affective environments and therapeutic landscapes that were created during sessions were integral to the benefits that participation entailed. Furthermore, it also allowed me to highlight the importance of cultivating

safe and supervised cultural environments that facilitate autonomy and choice in promoting engagement in physical activity in patients with advanced, incurable disease. Whilst qualitative research recognises the importance of context in understanding physical activity experiences per se, this depth of insight would not have been possible through the adoption of other qualitative methodologies.

This study also contributes to contemporary methodological discussions (see Bazeley, 2009; Brinkmann, 2015; Chamberlain et al., 2011; Gough & Lyons, 2016) on how we may seek to conduct high quality qualitative research. The methods and methodology used in this project support Brinkmann's (2015) assertion that qualitative research in psychology should be seen as a "craft" in which pluralism, creativity and diversity is embraced. In contributing to this methodological discussion, the following paragraphs reflects on how this research project was treated as a craft and in doing so seeks to provide insight that other qualitative researchers may find useful in working towards the types 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 & Lyons, 2016, p.239)

First, a pluralistic approach to data collection (Chamberlain et al., 2011) was adopted in which semi-structured interviews, participant observations, and informal conversations were utilised to provide insight on participants' views and experiences of hospice-based Tai Chi. These allowed me to work with participants in different ways, places, and times so that a rich, nuanced, and diverse understanding of their perspectives could be gathered (Chamberlain et al., 2011). Each of these techniques were able to provide "different takes" on the ways that participants viewed and experienced Tai Chi within the context of hospice day therapy in ways that were able to illuminate and enrich each other (Chamberlain et al., 2011). In doing so, it enabled me to understand my research questions in alternate and creative ways that would not have been possible through one data collection technique alone (Chamberlain, et al., 2011).

Second, methods of pluralism were also utilised when analysing data in this study. With regards to pluralistic data analysis, much attention has been placed on how researchers may combine various types of qualitative analytic techniques (i.e.,

thematic, narrative, phenomenological, grounded theory, discourse analysis etc.) in making sense of data in different ways (e.g., Clarke et al., 2015; Frost and Nolas, 2011, 2013). In complementing this type of analytic pluralism, this study offers novel insight of how we may use techniques such as "thinking with theory" (Jackson & Mazzei, 2018), attending to "outliers" (Phoenix & Orr, 2017), and creative non-fictions (Smith et al., 2015) as a means of thinking about, theorising and analysing data in creative ways.

For example, Jackson and Mazzei (2018, p.720) argue that the practice of "thinking with theory" is a novel way of analysing data which may "open up previously unthought approaches to thinking about what is happening in our research sites and encounters." Indeed, in this study, using theory to think about the data proved to be a transformative process in which I was able to go beyond simply describing the 'what's' of data and onto explanations of 'how's' and 'why's'. Borrowing theoretical concepts from diverse fields (e.g., health geography, sociology, and education) had the ability to "shake" me out of the understandings that I had become comfortable and accustomed to during initial data analysis (Jackson & Mazzei, 2018). In doing so, it opened up new ways of thinking about and conceptualising the data, particularly with regards to how theories such as affective environments and therapeutic landscapes helped to illuminate the importance of the cultural context in which participants' experiences of Tai Chi were located.

Furthermore, attending to outliers, or "exceptional data" (Phoenix & Orr, 2017), was another means through which I was able to analyse data pluralistically. As outlined in chapter 4.7.3, this was utilised as a secondary step *after* data analysis had been conducted and entailed searching for data that contradicted and challenged the dominant themes that had been constructed during initial data analysis. Through attending to exceptional data, I was able to explore alternative explanations which produced new ways of thinking about participants' experiences of taking part in hospice-based Tai Chi. For example, the outliers section in chapter 8 demonstrated how one participant struggled to see the value of Tai Chi and found engaging in visualisations difficult and silly, thus rendering it ineffective. What's more, it also presented Tai Chi as akin to a form of art which had to be mastered and experientially learned in order for participants to develop the "corporeal schemas" or "body techniques" that were fundamental to the benefits that were experienced.

Other examples of attending to outliers were the ways in which Tai Chi was a source of pain (see chapter 9.1.1, p.182-183), how an inward focus of the body could create a self-consciousness which accentuated participants' deteriorating bodies (see Debbie's creative non-fiction, p.147), and how the social interactions of Tai Chi were sometimes experienced as disruptive (see chapter 7, p.158). Attending to these outliers, therefore, highlighted how rather than the benefits of Tai Chi being experienced in a smooth, uniform, and linear fashion, they were often messy and complex. Thus, rather than discarding the pieces of data that made me uncomfortable and challenged initial ideas that I had developed, their integration did much work in enriching the end product and resulting in a more accurate, rounded, and rigorous analysis (Phoenix & Orr, 2017).

The final technique that was used as part of the analytic pluralism in this study were creative non-fictions (Smith et al., 2015). These were the short stories/vignettes that were crafted through drawing on literary and creative thinking techniques as a way to bring the raw data of this study "to life". It allowed me to invite readers into participants' visceral, sensory, situated, messy, and complex experiences of Tai Chi and QOL in ways that were not possible with conventional modes of representation. As well as using creative non-fictions as a means to assist readers in understanding participants' experiences in different and accessible ways, the process of writing also forced me into reflecting on my initial analysis of the data. In these ways the writing of creative non-fictions was:

> a method of inquiry, a way of finding out about yourself and your topic. Although we usually think about writing as a mode of 'telling' about the social world, writing is not just a mopping up activity at the end of the research project. Writing is also a way of 'knowing' – *a method of discovery and analysis*. By writing in different ways, we discover new aspects of our topic and our relationship to it. Form and content are inseparable (Richardson, 2000, p.923, emphasis added)

In line with the above quote, the process of writing and representation acted as a valuable form of analysis which invited me to think reflexively, critically, and creatively about what was occurring in the data (Smith et al., 2015). It also offered

the opportunity to *show* theory in action and weave in the nuance and complexity of participants' experiences of taking part in Tai Chi.

The techniques of pluralism discussed above may be thought of as a form of "bricolage" (Kincheloe, 2005). That is, a knowledge, and appropriate utilisation, of multiple methods of data collection, analysis, theory, and interpretation as a means to challenge existing understandings of phenomenon so that they can be appreciated in all of their complexity. As Kincheloe (2005, p.323) notes, "bricoleurs move beyond the blinds of particular disciplines and peer through a conceptual window to a new world of research and knowledge production". That is, through utilising multiple analytic techniques such as thematic framework analysis, thinking with theory, attending to outliers, and creative non-fictions, I was able to look at data from different angles and then use these insights as a means to build a textured, layered and rich analysis of participants' views and experiences of hospice-based Tai Chi.

10.3.1. A Reflection on (not) Leaving the Field.

Within ethnographic research, once fieldwork has been completed, it is common practice for researchers to physically leave the setting in which they conducted their research. This is often due to various reasons, including the depletion of resources (e.g., financial or practical) for carrying on with fieldwork and the necessity of starting the writing process (Hammersley & Atkinson, 2007; Wolcott, 2008). Whilst one's departure from the field is seen as an important aspect of ethnographies, however, very little has been written about how researchers may negotiate this process and the potential difficulties that they may encounter in doing so (Iversen, 2009). This is an important omission considering that Hammersley and Atkinson (2007, p.95) recognise that leaving the field 'is not always a straightforward matter'. This is because many of the characteristics that give ethnographies its strengths (e.g., relational embeddedness and intensive contact with cultures over prolonged periods of time) can make exiting the field a complex and difficult process (Iversen, 2009). Issues that may contribute to difficulties in disengagement include the researcher developing strong connections with study participants and becoming thoroughly embedded within the landscapes/settings in which they have conducted their work (Hammersley & Atkinson, 2007; Iversen, 2009). This means that the ways

in which participants perceive the researcher's role can easily become blurred (Iversen, 2009).

Resonating with the above, in the context of this study, I found that my dual role as a researcher and volunteer within the day therapy unit of the hospice contributed to the complexities and dilemmas that I faced when it became time for me to consider leaving the field. This was for various reasons. Firstly, volunteering at the hospice was something that I really enjoyed doing. This was predominantly because throughout my initial 8 months, I developed a close and very genuine connection to the hospice and the patients and staff that were there; in other words, being able to be at the hospice became a genuinely important part of my life and it was something that I cared deeply about. Secondly, (and related to the aforementioned point), was that throughout my time immersed in the field, I realised how imperative volunteers were in ensuring that the day therapy unit (and the hospice more generally) was able to function and provide the type of holistic care that is so important to ameliorating patients' quality of life. For example, it is the volunteers who assist with the various activities that patients engage in during their day's stay, sit and make conversation with patients, make cups of tea, serve lunches, and generally assist the healthcare professionals in any way possible to help alleviate their (often top-heavy) workload. I also knew (from the comments of staff and patients) that my role in fulfilling these tasks was extremely valued throughout my fieldwork and, because of this, I was considered as an integral part of the day therapy team.

Consequently, from a personal, moral, and ethical standpoint, I felt uncomfortable in suddenly exiting the field once data collection (thus the role of being a researcher) had finished, especially because the staff and patients at the hospice had given up so much of their time, energy and patience in making this research project possible. In seeking to balance reciprocity, therefore, I felt it my duty to continue my volunteer role within the day therapy unit once fieldwork had ended. In this way, after fieldwork had finished, whilst I was still physically present within the day therapy unit in a volunteer capacity, I had relinquished my role and duties (thus left the field, so to speak) as a researcher. At the time of writing this thesis, this has equated to volunteering within the day therapy unit for a period of 3 years. In this time, it is arguable that, in many ways, the field left me. This is in the sense that the

patients who took part in this study left the day therapy unit once their needs were met and/or sadly passed away. By reflecting on how the field, or at least participants who were part of the field, left me adds new insight into how ethnographers working within palliative care contexts may theorise about, and navigate the process of, 'leaving the field'.

10.4. Potential Limitations and Future Possibilities

As with all research projects, this study has various potential limitations, many of which revolve around sample bias. The majority of individuals who took part in this study were female day therapy unit patients who were enthusiastic about, and obviously found some benefit through participating in, Tai Chi. This presents potential boundaries with regards to the types of populations that the data presented in this thesis may represent. Because of this, it is arguable that the bulk of findings presented between chapters 6-9 paint only part of the picture with regards to the wider Tai Chi experiences of patients within this population. These limitations (amongst others) are now outlined with recommendations on how future research may seek to address them in ways that can further deepen our understanding of Tai Chi (and other similar interventions) experiences within a palliative care context.

First, the sample of this study comprised of patients who were self-selected and (on the whole) enthusiastic about taking part in Tai Chi. Although the research team endeavoured to recruit patients who did not always take part in (and perhaps did not always benefit from) Tai Chi, many of these individuals were uninterested in taking part in interviews and observations because they felt as though their accounts were unable to offer much in the way of understanding the role that Tai Chi had on their QOL. The views and voices of this sub-section of patients within the day therapy unit, therefore, are arguably under-represented by the data presented in this thesis. It is, perhaps, that Michael's accounts (which was predominantly represented in chapter 8) allow us an introductory and partial insight into the views and experiences of these types of patients, however, this was by no means to the same depth and breadth as the other findings presented in this thesis. Consequently, in forming a more accurate, rounded, and comprehensive understanding of Tai Chi experiences within this context, future research may be enriched through widening

the types of participants it recruits so that it includes patients who may not always identify positively with Tai Chi.

Second, another potential limitation with regards to sample bias is that the majority of this study's sample (e.g., 79%) were female. One possible explanation for this was that it tended to be male patients who were sceptical in taking part in Tai Chi (thus this project) for reasons outlined above. Furthermore, because Tai Chi required patients to connect inwardly and self-reflect on oneself, one may postulate that these patients (many of whom had previously served in the forces and engaged in sports such as rugby, football, and boxing), might have been reluctant to participate as they saw it as a "feminine" or "airy fairy" form of physical activity. This was certainly the impression that I gathered through being immersed in the field before, during, and after my data collection. Accordingly, whilst the accounts of male and female participants in this study did not seem to differ, it is conceivable that the experiences of hospice-based Tai Chi presented in this thesis are in some ways gynocentric. Future research, therefore, may seek to recruit more males to their samples, particularly those who do not always "buy into" Tai Chi. One potentially fruitful area for researching male views and experiences of Tai Chi within hospice settings could be to explore how they intersect with, and are influenced by, their perceived masculine identities.

Third, it is also important to bear in mind that the palliative population is diverse and represents a wide continuum of patients with varying levels of disease progression/severity. For example, within the stage of advanced, incurable disease, those earlier on in the disease trajectory can be fairly independent and able to engage in a range of physical activities (e.g., walking, swimming, cycling). In contrast, the bodies of patients falling at latter stages of the disease trajectory are often severely deteriorated and find even the simplest of tasks (e.g., walking across a room) extremely difficult. Predominantly (whilst by no means exclusively), it is the former, less deteriorated types of patients who receive day therapy hospice care, compared to the latter who are often cared for on in-patient units and the community. Therefore, it remains to be seen if the benefits that were experienced through taking part in hospice-based Tai Chi by day therapy patients in this study would be the same as patients further on in the advanced disease trajectory. Future research should seek to address this question to further our understanding in this area.

Aside from sample bias (yet related to the above point) is another potential limitation of this project. That is, the findings presented in this thesis have been culturally located, thus made sense of, within the context of hospice day-therapy. This represents only one facet of hospice palliative care which also spans in-patient units and the community. These locations of palliative care occupy different spaces, places, and (possibly) values to that of day therapy units, therefore it is unclear whether the benefits experienced through taking part in Tai Chi within the hospice day therapy unit extends to other settings where palliative care is delivered to patients. Future research – ideally guided by focused ethnographic methodologies – would contribute significantly to understanding how patients' views and experiences of Tai Chi (and other mind body and physical activity interventions) are embedded within these different settings.

That said, focused ethnographies are not the only qualitative methodology which researchers may use in seeking to enrich understanding in this area of research. Indeed, whilst this project was fundamentally an ethnographic piece of work, it borrowed ideas and concepts from other qualitative approaches, including narrative (e.g., use of narrative templates and stories to understand and represent illness and Tai Chi experiences) and phenomenology (e.g., the importance of the lived body during Tai Chi). Ideally, I would've liked to have analysed my data-set through various types of narrative (e.g., holistic/categorical-content and dialogical narrative) and phenomenological (e.g., interpretive phenomenological) lenses as a way to push my understanding of research questions even further. Time and space limitations meant this feat exceeded the scope of this PhD. However, in working as analytic "bricoleurs" (Kincheloe, 2005), these types of approaches (amongst others) provide fertile grounds for future inquiry and allow researchers the opportunity to provide "different takes" (Chamberlain et al., 2011) on patients' experiences of Tai Chi, and other forms of physical activity, in this context.

10.5. Concluding Thoughts

"The thing about Stage Four is that there is no such thing as Stage Five" (Hitchens, 2012, p.41).

The words of Christopher Hitchens – which I used to open this thesis - captures the profoundness of advanced, incurable disease. As this thesis has

demonstrated, the multiple fears and losses that are associated with terminal illness can shatter and disrupt an individual's QOL. Uncontrollable and unpredictable physical deterioration can mercilessly control a patient's ability to live independently, reducing them to what seems to be a life of perpetual discomfort and pain. What's more, as their illness progresses, and they become confined to the four walls of their homes and reliant on the help and care of others, patients often become isolated and feel as though they are a burden to friends, family, and healthcare services. Thus, whilst terminal illness can be an opportunity for growth and enrichment, for some, overriding the entire process of dying is a distinct sense of sadness, anxiety, and worry. Living with stage 4 illness, however, does not have to have to condemn an individual to a life of misery and distress. Despite the challenges that patients with terminal illness may face, palliative care plays a crucial role in providing them with solace from what can feel like an unrelenting battle against their own body and mind. It does so through taking a multidisciplinary and holistic approach towards improving QOL. One aspect of palliative care's multidisciplinary approach to achieving this is rehabilitation. This seeks to empower patients and help them to "adapt to their new state of being with dignity" through helping them to "anticipate and cope constructively with losses resulting from deteriorating health (Hospice UK, 2015, p.2).

This thesis has demonstrated how Tai Chi presents an apt intervention which fits directly within the ethos and goals of rehabilitative palliative care. Through integrating gentle body movements, breath-work, and mindfulness, Tai Chi unifies the mind, body, spirit, and environment in ways that can simultaneously address the multiple issues that patients with life-limiting diseases face. Indeed, this PhD project has demonstrated the role that it may play in helping patients craft what it means to live with a terminal illness. By grounding their minds and bodies in the present moment and allowing them to experience them in pleasurable and peaceful - as opposed to chaotic and distressing – ways, Tai Chi helped participants to (re)learn and (re)shape how they felt and thought about their body and minds. Furthermore, taking part in Tai Chi with other patients who had a shared, experiential understanding of terminal illness provided a sense of comfort and connection at a time in their lives when they often felt misunderstood and lonely. Participants utilised Tai Chi as a platform through which they could use their own understandings of

illness and suffering to reach out and support others who were going through the same thing, thus work together in coping with adversity.

A theme that has ran through this entire thesis - and something that was observed over and over again in the field - was the importance of the hospice's day therapy unit in which participants' experiences of Tai Chi were located. In short, the day therapy unit provided a unique socio-cultural context in which participants felt confident and sufficiently supported in using mindful movement to be proactive in dealing with their illness. Accordingly, because they are one of the only places in which patients with life-limiting illnesses may be able to benefit from mindful movement (and other physical activities), hospices should see themselves as "diffusers" (McLeroy et al., 1988) of these types of interventions within the local community. Ultimately, by integrating mindful movement therapies (such as Tai Chi) – and physical activity more generally - as an integral part of their multidisciplinary and holistic approach to improving QOL, hospices can further work towards achieving the fundamental goal of palliative care: to help patients live until they die.

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Appendix A: Patient information sheet

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Participant Information Sheet

Study Title: Physical activity and quality of life in palliative care.

We would like to invite you to take part in a PhD research project investigating your views of Tai Chi sessions here at Wheatfields and how these impact your quality of life.

Before deciding whether or not you would like to take part, it is important that you understand what participation involves.

Please read the following information and discuss it with friends, family, and/or your health professionals if necessary.

A member of the research team and/or staff at Wheatfields will be available to discuss this information sheet with you and answer any questions that you may have regarding your participation. Finally, we would like to stress that participation is completely voluntary and that should you wish to do so, you can withdraw from this study at any point.

Summary/Purpose of Study

For those receiving palliative care, exercise can have positive effects on physical and mental well-being. Tai Chi might be a crucial part of palliative care services to help improve physical functioning and maintain well-being during illness. However, our understanding of how Tai Chi impacts quality of life and palliative care experiences is limited. We also do not know much about what helps or hinders taking part in such programmes.

At Wheatfields Hospice, we are interested in your views and opinions on the benefits of Tai Chi. We are seeking feedback about patients' experiences of the Tai Chi programme and how they feel it has impacted their quality of life. It is hoped that this information will improve Tai Chi sessions at Wheatfields and assist in improving the quality of life for our service users.

What is involved?

If you choose to participate in this research, you will be invited to take part in three one-to-one interviews (the first being once you have started Tai Chi sessions, the second about two weeks later and the third about four weeks later) at a time most convenient to you. With your consent, interviews will be audio recorded and are

estimated to take between 30-60 minutes. The researcher will ask you questions regarding your experiences of the Tai Chi sessions.

The researcher will also actively participate in Tai Chi sessions where they will observe and take notes on group behaviours, interactions and dynamics exhibited by patients during the Tai Chi session and throughout your day visit at Wheatfields.

With your additional permission, the Wheatfields team will provide the researcher with information on your current diagnoses, symptoms and treatments. This will help the researchers understand how these relate to the findings of the research.

If you are interested in participating in this study, you will be invited to meet with a researcher at Wheatfields Hospice, at a time most convenient for you, to discuss the study further and ask any questions that you may have. If you then decide to take part in this study, you will be required to give written informed consent. This will involve the research team ensuring that you are fully aware of what your participation entails. You will then be asked to sign a form stating that you fully understand the nature of the research and are happy to take part.

When would I take part?

Interviews and observations will be conducted during your visits to the Wheatfields day therapy unit. Although interviews are expected to last around 30-60 minutes, this time is flexible. If at any point you want to take a break from or finish the interview, or if you want to withdraw from the study altogether, please let the interviewer know.

What are the possible benefits of taking part?

Patients who take part in interview studies commonly enjoy having the opportunity to talk about their views and experiences. Some patients also feel that interviews provided them with an opportunity to have their say about the way in which future services should be developed.

What are the possible disadvantages of taking part?

The interviews will include discussion of your illness experiences and some people may find this upsetting. If at time any you feel that you would like to talk with a member of the Wheatfields team about your feelings and experiences, please let the researcher know. If required, we will be able to arrange further support for you.

What if something goes wrong?

In the unlikely event that something goes wrong and you are harmed during the research due to someone's negligence then you may have grounds to take legal action. Leeds University are sponsors of this study and have a Public and Products Liability policy which covers the activities of this study and the activities of its' researchers. If you are unhappy with any aspect of this study, you are encouraged to voice your concerns to either the research team or staff at Wheatfields using the contact details provided below.

What happens with the data collected in this study?

All information that we collect during the study will be anonymised and confidential. Pseudonyms (fake names) and participant ID numbers, will be used to ensure that you cannot be identified outside of this study. All documents containing personal

information will be securely stored on password protected files and in locked cabinets of the researcher's office at the University of Leeds. Only the research team will have access to these files/documents. Documents and audio-files will be stored for a period of up to 5 years following the completion of the study.

What happens with the results of this study?
The results of this research will be used to inform members of staff at Wheatfields of your views and experiences of Tai Chi sessions and how these affect your quality of life. With this information, they will be able to improve the quality of Tai Chi sessions. Results will also be used for the completion of a PhD project thesis and may be published in academic journals. If you or your family members want feedback, or have questions regarding the findings of this research project, this can be arranged through contacting either Dr Shaunna Burke or Andrew Bradshaw (see contact details below).

We will not share any of the discussions that take place in the interview with family members, carers, or Wheatfields staff unless you say something to the researcher that gives them cause for extreme concern for your personal safety or well-being in which case they will report this to an appropriate member of the medical team.

What will happen if I don't want to carry on with the study?
Participation in this study is completely voluntary. If for any reason you feel that you do not want to take part any more, you are free to withdraw at any time, without reason and your data will not be used. You will not need to attend any further interviews and the researcher will not take notes on any interactions involving you during Tai Chi sessions. Withdrawing from this study will not affect the support services that you receive here at Wheatfields.

Who has reviewed this study?
To protect your rights, safety and well-being, this research has been looked at by a Research Ethics Committee. Favourable opinion for the conduct of this study has been given by South Central Oxford B Research Ethics Committee.

What now?
Thank you for taking the time to read this information sheet. If you decide that you would like to take part in and/or have any questions/concerns regarding this study, please talk with a member of staff at Wheatfields or get in touch with the research team using the contact details given on the last page of this information sheet.

Wheatfields Staff:

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Appendix B: Consent Form

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Patient Consent Form

Title of Project:

Physical activity and quality of life in palliative care: Exploring patient's experiences and views on participation in a tai-chi programme at Wheatfields hospice.

Research team: Dr Shaunna Burke (s.burke@leeds.ac.uk)

Andrew Bradshaw (sp12a2b@leeds.ac.uk)

Please initial each box to show that you have read and agree with each statement:

I confirm that I have read and understand the information sheet dated […………] version [….] for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	☐
I understand that interviews will be audio recorded and I agree to such recordings taking place, in the understanding that all published data will not include any personally identifiable information (that my contribution will be anonymous)	☐
I understand that the Wheatfields team will provide the researchers with information on my current diagnoses, symptoms and treatments. I give permission for these individuals to have access to this information for the purposes of this research.	☐
I agree to take part in this study.	☐

Name of Patient _____ Date_____ Signature_____

Name of Researcher_____ Date_____ Signature_____

Appendix C: Interview Guide 1

Patient Interview Topic Guide

Patient Interview Topic Guide

This is a sample topic guide for interviewing patients. This guide will be updated and reviewed during the interview process to target emerging themes and new topics of interest.

<u>Welcome and study information</u>

Thank you for agreeing to help with this research. Here at Wheatfields, we are reviewing the benefits of Tai Chi for patients who use our services. We are inviting patients to attend interviews to tell us about their views and experiences on participating in Tai Chi sessions and how taking part affects their quality of life.

Everything that you say during this interview is confidential and will not be passed on to your family members, or health professionals without your consent. It is possible that some of the things you say during the interview will be quoted in reports for Wheatfields and Sue Ryder. We may also include quotes from interviews in future research publications. If that happens, the quotes will be anonymous – which means that we will not use your name or say anything about you that may make you identifiable.

Initially I am going to ask you to talk about your illness in general. We will then talk about your personal views and opinions on Tai Chi here at Wheatfields and what helps or hinders you taking part in these sessions. Finally, we will speak about how these sessions have impacted different aspects of your quality of life and palliative care experiences.

There are no right or wrong answers to any of the questions; we are just here to learn more about you and your experiences. As we go along, if there are any questions that you would rather not answer, this is fine, just let me know and we will move on. We can stop the interview at any time, particularly if you feel tired or unwell, just let me know.

Is there anything you want to ask me about?

I am going to turn on the Dictaphone now if this is OK with you?

[The style of the interview will be open ended so the following are topic guides, we are encouraging patients to talk about issues that they feel are important]

- Can you tell me a little bit about yourself and your background?

    o What illness do you suffer from?

    o What treatments have you received for this illness?

    o What is your living situation (i.e. where and who do you live with)?

- I have been a volunteer at the hospice, but this is very different to being a patient; if I could put myself in your shoes, what would a typical day at [hospice name] look like?

    o What was it like to initially come to [hospice name]?

        ▪ What feelings and emotions were you going through on your first day?

    o Since then, how have you experienced social environment at [hospice name]?

        ▪ What is your relationship like with nurses, physio's, volunteers, other patients

        ▪ How does interacting with these people impact how you find your time here?

Section 1: Patient's perceptions of the meaning and experiences of quality of life

- I'm going to ask a different type of question now. It focuses on quality of life, something which means different things for different people. I was wondering what quality of life means to you?

    o How would you define it?

    (A) How has your illness (and associated treatment) influenced your physical well-being (i.e., pain, fatigue levels, mobility)?

    (B) Psychological well-being (i.e., sense of control, etc)?

    (C) Social well-being (i.e., social interactions)?

    (D) Spiritual/existential well-being (i.e., maintaining hope and deriving meaning)?

    o How would you describe your quality of life since diagnosis?

o Looking ahead to the future, do you have any concerns, or fears? What is most important to you as you move forward during your illness?

Section 2: Initial Views and Experiences of Tai Chi

[*Explain that Tai Chi has been linked to an improved quality of life as a way to introduce this topic/section of the interview*]

- What have your initial views and experiences of Tai Chi been?

    o Why did you/have you decided to participate in the classes?

    o Could you talk to me how you have experienced Tai Chi?

        ▪ Social side of it being in a group

        ▪ Relaxation

        ▪ Inclusivity and Patient-Centred

    o Reiterate *their* conceptualisation of quality of life (i.e. what they said in their own words) 'so you said that quality of life meant this to you' … do you feel that taking part in these Tai Chi sessions have had any impact on your quality of life?
        ▪ Physical

        ▪ Psychological

        ▪ Social

        ▪ Existential

    o Do you have any concerns regarding your participation in the sessions? If yes, please explain.

Section 3: Barriers and Facilitators

- Is there anything that makes taking part in sessions difficult?

- Is there anything that makes taking part in sessions easier?

- Discuss any other points that the patient wishes to focus on.

- Summary, thanks, debrief and close.

Appendix D: Interview Guide 2

Section 1: Patient's perceptions of the meaning and experiences of quality of life

- The last time we met, we spoke about quality of life and what it means to you? How have your perceptions of QOL changed since the last time we spoke?

    o Have your priorities in terms of what is important in life to you changed?

Section 2: Patient's Experiences of Tai Chi and QOL

General

- What do you hope to achieve when you participate in Tai Chi sessions?

- Do you feel as though there are any unwritten rules that guide the Tai Chi sessions and if so what do you think they are and how do they affect your experiences?

Physical and Psychological (mind-body)

- How does it feel to have the opportunity to be physically active and move your body during Tai Chi?

- Quite a lot of people have spoken about how they experience relaxation when taking part in the Tai Chi. Could you tell me what is it exactly about the Tai Chi sessions that is relaxing? (i.e. music, movement, or combination of both)

    o How has this relaxation impacted you after and outside of Tai Chi sessions?

    o How have the benefits of relaxation you gain from Tai Chi impacted your QOL outside of [hospice name]

- How have you experienced the visual/imagery aspects of Tai Chi?

    o How have you experienced the link/relationship between your mind (i.e. visual aspects) and body (i.e. physical) during Tai Chi?

    o How has this impacted your QOL?

- Some people have talked about how there is a meditative aspect to Tai Chi. Would you say that you've experienced this? What has this experience been like for you?

- Does this help provide you with respite/escape from the reality of your illness? How so?

- Is it an opportunity to think clearly and peacefully?

    o In what ways do you feel that this has impacted your QOL?

Social

- How have you experienced being around other people whilst taking part in Tai Chi at [hospice name]?

    o I have noticed that all of the Tai Chi sessions are conducted in a circle? How have you experienced doing Tai Chi with others in that particular shape?

        ▪ Do you feel an element of connectedness/inclusivity with others when performing Tai Chi here?

        ▪ How has doing Tai Chi with other people had an impact on your QOL?

- I know that some patients have taken the Tai Chi music CD home. Is this something that you have done?

    o What is the difference between doing Tai Chi/listening to the CD at home as opposed to with other people at [hospice name]

- I have observed a lot of people smiling, laughing, and joking during the Tai Chi sessions. Would you say that there is an element of humour when doing Tai Chi? How does this make you feel?

    o How has the humour and light-heartedness aspects of Tai Chi impacted your QOL?

Existential

- How has taking part in the Tai Chi sessions (i.e. being able to be physically active with other people) influenced how you view your purpose in life?

Section 3: Barriers and Facilitators

- Is there anything that makes taking part in sessions difficult?
        ▪ Illness-related
        ▪ Not illness-related

- What makes, or could be done to make taking part in Tai Chi easier?

- How has the way in which the physio's deliver the Tai Chi impacted your experiences of it?

- For example, do they deliver Tai Chi in a way that accommodates to your needs? (i.e. to your illness, symptoms, abilities)?

- Is this an important aspect of Tai Chi for you? Why?

- How do you feel about the physio's guiding you through the movements?
    - Does this help to create a safe and reassuring environment?

- Is there anything that you would you change any about Tai Chi?

Appendix E: Tai Chi Guide

Adapted Tai Chi

Chair-based exercise programme for DTU

Introduction

- The programme is tai chi based (not pure tai chi)
- Benefits

  - relaxation
  - improve coordination and balance
  - based around gentle efficient movement (flowing movements)
  - engages mind and body
  - help control breathing

- Instructions

  - Keep breathing! (breath with the movement)
  - Work within own limits (rest as required, don't push through pain, people with heart and lung problems to avoid too many overhead exercises)
  - Avoid extreme twisting and bending if you have spine problems e.g. osteoporosis or bone mets
  - LISTEN TO YOUR BODY

- Posture / positioning (demonstrate)

  - Seated throughout — choice of 3 positions.
  - Lengthen the spine, pull up from the crown of your head, chin tucked in, shoulders back
  - Relaxed not rigid

Warm up

- Shoulder rolls – forwards and backwards
- Alternate arm swing (floppy)
- Marching legs
- Finger flicks (finger flexion / extension)
- Thumb to alternate fingers
- Shaking hands (as though shaking off water, move at wrists)
- Heel and toe (ankle movements)
- Cherry picking (bowl, tree, table)
- Trunk rotations (rest arms)

Main Exercises

1. Waterfall (trunk ext. if possible)

   - Raise both arms to shoulder height then lower — or if balloons attached to them that lift arms
   - Keep wrists and hands relaxed

2. Supporting a ball in front of the shoulders

   - Imagine resting a ball on the palm of one hand
   - Take the ball towards your opposite shoulder — support ball on hand
   - Slight twist at the waist — then push ball down into water

3. Kick with the sole

   - Knee extensions

4. Spring and autumn

   - Raise arms to shoulder height
   - Take arms out to side then back in front of chest
   - Lower

5. Pushing the waves (one foot in front of other.)

   - Hands in front of chest
   - Push forwards with hands
   - Pull back with hands
   - Move body back and forwards as hands move

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6. Stepping over the puddle (hip abduction)

   - Step one leg out to the side then return to centre
   - Swap legs

7. Flying dove spreads its wings

   - Lift arms out to the side and lower as if flying / wings

8. Cloud hands — scoop up cloud + look at it.

   - Palm facing in, lift one hand up in front of face then slightly out to the side and lower, swap hands
   - Follow hands with head throughout movement

9. Dipping toe in the water (heel and toe touches)

   - Extend one leg and tap toe on floor
   - Swap legs

10. Punching ($\bar{c}$ pro + supination)

   - Punch out in front, one hand at a time, relaxed fist

11. Stepping and bouncing a ball

   - Lift one knee and the opposite hand at the same time then lower and repeat with opposite knee/hand

12. Balancing the chi to close
   - Imagine scooping up cooling water to your face

Cool Down

Relaxed breathing (gentle tummy breathing – not big breaths or holding breath – take in just the air you need)