INTEGRATING THE MIND AND THE BODY: EXAMINING THE ROLE OF COUNSELLING PSYCHOLOGY FOR INDIVIDUALS WITH PHYSICAL HEALTH PROBLEMS

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THE FOLLOWING PART OF THIS THESIS HAS BEEN REDACTED FOR DATA PROTECTION/CONFIDENTIALITY REASONS:

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I hereby declare that the work presented in the thesis is my own and has been developed under the supervision of Carla Willig and any other assistance as stated and referenced in the thesis accordingly.

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The aim of this portfolio is to investigate the link between the mind and the body in people who have physical health problems. There has been a long established link between the effects of the mind on the body. The media is constantly bombarding us with information about the detrimental effects of stress to our health. There are terms such as 'Type A' behaviour that increases our risk of heart disease and 'Type B' behaviour that inflates our chances of getting cancer. Consequently we are all aware of the behaviours that are likely to harm our health. However there is less attention on the link between the mind and the body in those people who are already facing serious health problems. Once a person receives a diagnosis of a chronic or terminal condition, the reaction a person has is likely to influence the way they experience their body and their symptoms. Similarly the way a person feels physically is likely to have an effect on their emotional well-being. Therefore this portfolio aims to investigate the experience and psychological mediation of physical health problems for those individuals who are already ill. The findings are hoped to inform Counselling Psychologists of how they might support people facing serious health problems.

I have always been fascinated by the link between the mind and the body and the three pieces of work presented within this portfolio have been inspired by my work with people with physical health problems over the years. The main piece of research is a study looking at the experience of spirituality and meaning-making in individuals with advanced cancer. During my training as a Counselling Psychologist I worked as a research assistant for the Marie Curie Palliative Care Research Unit. My role was to give people with advanced cancer questionnaires measuring their spirituality and physical and emotional health. Visiting these participants in their homes was fascinating and I was told many stories long after the individuals had filled in their questionnaires. On more than one occasion I was asked if there is any qualitative research being done on spirituality at the end of life as people had so much to say. I found myself drawn to this area because I felt Counselling Psychology can contribute a lot to supporting people at this stage of life. I chose to explore spirituality through interviews to give a greater insight into the individual's experience of making sense of

life as they approached their death. An existential approach was taken to the research since this is an area of psychology that deals with the "big questions" about the meaning and purpose of life. The aim of the research is therefore to give Counselling Psychologists working in this area a greater understanding of the issues individuals with advanced cancer face so they are equipped to tackle the "big questions" in therapy.

The second piece of work is a case study based on my current work at a Clinical Health Psychology department. The department has seen an overwhelming increase in the number of referrals for people with health problems facing emotional difficulties over the last few years. This department is well established within the hospital and the case study presented shows the importance of the role of Counselling Psychologists working with health problems. The client is a 40-year-old gentleman who has been diagnosed with ulcerative colitis. Being diagnosed with a chronic health problem was overwhelming for this client and his anxiety about exacerbating his condition affected every facet of his life. He was referred as part of a study looking at the efficacy of cognitive-behavioural therapy on medically ill clients, and the study examines the application of the cognitive-behavioural model for health anxiety. The objective of presenting this material is to illuminate the challenges of working with clients using a cognitive-behavioural approach for health anxiety given that they already have medical problems.

The final piece is a literature review looking at the benefits of psychodynamic counselling for people with dementia. Before starting my training as a Counselling Psychologist I worked as a dementia advocate for a charity. I found during my experience that there was a large focus on the practical support for people with dementia and their carers. The therapy services I encountered during this time only catered for carers yet during my many visits to peoples homes, it was clear that people with dementia were in need of emotional support as well. The review presented examines the application of psychodynamic therapy for people with dementia, but it is expected that other models could also be suitable. The aim of reviewing the literature was to inform Counselling Psychologists about the application of therapy to this population and examine if psychodynamic therapy is an appropriate technique. Also

given that researching people with dementia is a challenging area, the findings are intended to highlight the methodological issues to inform future research in this area.

Together the three pieces of work look at the experience of cancer, chronic health conditions such as colitis and dementia using existential therapy, cognitive behavioural therapy and psychodynamic therapy. Thus the work shows the diversity in models that can be used for different health problems and different issues that the clients present. As a collective the portfolio is intended to further the understanding of the experience of chronic and terminal health and illuminate the vital role of Counselling Psychologists working in this field.

PART I

DYING-IN-THE-WORLD: THE EXPERIENCE OF SPIRITUALITY AND MEANING-MAKING FOR PEOPLE WITH ADVANCED CANCER

ABSTRACT

Finding meaning when facing a diagnosis of advanced cancer can be an important part of an individual's experience as they face the reality of their death. Spirituality has frequently been cited as an important source of meaning, yet there lacks a consensus over what this term actually means. Previous literature has encountered serious methodological problems, such as confounding religion with spirituality, and there is a lack of qualitative studies in this area. The current study explored the experience of spirituality and meaning-making at the end of life in eight participants with advanced cancer. A hermeneutic phenomenological method was employed since this was considered a creative approach to explore such an elusive concept. The transcripts were turned into poems using poetic condensation (Gee, 1991) in order to preserve the emotional content of the narrative. Analysis revealed two modes of being available to participants at this stage of life: the everyday mode of being and the transcendent mode of being. Participants in the everyday mode of being found meaning from relationships with others and their environment. It is argued that the term "spirituality" is not relevant for this mode of being since participants did not connect with this terminology. Instead the term "belonging-in-the-world" is proposed to capture their experience. For individuals in the transcendent mode of being, meaning was created by thinking about the order of the universe or world and seeking comfort from their inner world. It is proposed that the term spirituality is relevant to their experience. The two modes of being were not mutually exclusive and there was context found that influenced movement between the two. These included treatment history, family and relationships and experience of death throughout life. The appropriateness of existential therapy for participants in the advanced stages of cancer is explored and recommendations are made for future research in this area.

1. INTRODUCTION

1.1 Overview

Frankl (1962) claimed that meaning-making is the primary motivating force within humans. Receiving a diagnosis of cancer often leads individuals to question the meaning of life as they face the reality of their own death (Jim, Richardson, Golden-Kreutz, and Andersen, 2006). Spirituality is frequently cited as important in meaning making (Yalom, 1980) and the majority of patients with a terminal illness consider themselves to have spiritual beliefs (King, Speck and Thomas, 1995). However there remains much debate over what the term spirituality incorporates. Nevertheless researchers have attempted to create a quantifiable measure of spirituality, which has then been used to compare spirituality with other health outcomes. However much of the research involves poor methodological rigour leading to limited conclusions to be drawn from the results (Thune-Boyle, Stygall, Keshtgar and Newman, 2006). The current study aims to go back to the roots of spirituality research and explore what this concept means for the individual facing advanced cancer. The findings of the study are aimed to inform all healthcare professionals in the field of palliative care, since spiritual needs are often ignored (Walter, 1997). The results are also thought to be of particular relevance to counselling psychologists working with individuals at the end of life, given that they are in a "pivotal position" to explore meaning making at the end of life (Carr, 1995).

The following chapter begins by looking at the contributions of Victor Frankl (1962) to the notion of meaning-making. How this concept fits into existential theory is explored followed by a review of how spirituality is discussed within existential literature. A summary of the research that suggests that meaning is important to individuals with advanced cancer is presented, supported by the findings of Greenstein and Breitbart (2000), who set up a meaning centred group for individuals with advanced cancer based on Frankl's (1962) book, *Man's Search for Meaning.* Spirituality as a source of meaning-making for individuals with advanced cancer is considered followed by an acknowledgement of the difficulties of defining such a term. Despite being difficult to define, a number of instruments have been developed

claiming to capture spirituality.   How these instruments have been used for research and the methodological problems these studies face will also be explored within this text.   It is concluded that more research needs to be conducted in order to find out what spirituality means for people with advanced cancer.   Thus a review of the current literature exploring the experience of spirituality in this population is conducted, finishing with a lead into the current study.

1.2 Man's Search for Meaning

1.2.1 Victor Frankl

In his book *Man's Search for Meaning*, Victor Frankl (1962) stated that the need to find meaning in one's life is not just a coincidence but the primary motivating force within humans. He claimed that meaning always exists, right until the last moment of life, which is unique and specific to the individual and can be created by him alone. According to Frankl (1962), meaning falls into three categories. Firstly, meaning can be derived from what one gives to the world, such as creating work or doing a deed. Alternatively meaning can involve experiencing something within the world, such as goodness, truth and beauty or experiencing another human being through love. Finally in situations where the individual is facing unavoidable suffering, meaning can still be found in ones attitude towards suffering or a fate that cannot be changed*; "When we are no longer able to change a situation – just think of an incurable disease such as inoperable cancer – we are challenged to change ourselves"* (Frankl, 1962; p. 135).   The latter category was based on Frankl's own experience of Auschwitz where his determination to survive and write his manuscript gave meaning to his life despite enduring the atrocities of the concentration camp.

From his theory, Frankl (1962) devised "Logotherapy" (*logos* from the Greek word denoting meaning), which he claimed helped individuals discover their own why to live so they could bear any circumstance. Frankl (1962) observed that many people today feel that their lives lack meaning, manifested as a *"void within themselves"* (p128; Frankl, 1962) which he termed the 'existential vacuum'.   Although not

supported by any evidence, Frankl (1962) claimed that at least a third of his clinical cases were people suffering from neurosis as a direct result of lack of meaning in their lives. Thus Frankl regarded existential neurosis as synonymous with a crisis of meaninglessness (Yalom, 1980). Accordingly, Logotherapy attempts to make the individual responsible for finding their own meaning, leading to a transcendence of the self once the person finds meaning in something or someone beyond themselves (Frankl, 1962). Therefore even in terrible circumstances a person could turn the situation into a triumph if they take the opportunity to grow beyond themselves and find meaning.

1.2.2 Meaning as an existential concept

Creating meaning in one's life is a central concept in existential philosophy. Existentialism, originating from the nineteenth century thinkers such as Kierkegaard (1844; 1983) and Nietzsche (1885; 1961), seeks to answer questions in life such as, "what is it worth living for?", "what is the purpose in my life?" and "is there meaning in my life?" (Reker, 2000). Over the years there have been many perspectives on existentialism, however all theories follow a common set of beliefs based around the notion that individuals attempt to make sense of their existence by assigning meaning to it and taking responsibility to act accordingly. A person with a high degree of existential meaning is thought to have a clear direction in life leading to life satisfaction and a determination to make the future meaningful (Reker, 2000).

Yalom (1980) claimed that meaning is one of the "givens" in life (the others being death, isolation and freedom) and when individuals are faced with these givens or truths, they fall into despair. Yalom (1980) postulated that human beings need meaning, since to live without meaning, goals, values, or ideals can lead to distress or even suicide. However the "given" of freedom means that there are no absolutes since the world is contingent and everything could have been another way. Therefore *"human beings constitute themselves, their world, and their situation within that world, that there exists no meaning, no grand design in the universe, no guidelines for living other than those the individual creates"* (Yalom, 1980. p. 423). How does one find meaning in a universe that has no meaning? The purpose of existential

psychotherapy is therefore to help people find ways of making sense of these questions (van Deurzen-Smith, 1988).

Unlike more traditional philosophies, such as rationalism and empiricism which aim to seek ultimate order and universal meaning, existentialism argues that humans define their own reality. For example, Heidegger (1927; 1962) postulated that individuals cannot be separated from the world they inhabit, and thus he referred to humans as *Dasein,* meaning being-in-the-world. We are thrown into the world, without choice, into a particular set of circumstances (Heidegger, 1927; 1962). Therefore according to Heidegger (1927; 1962), people can not discern objective truths, and instead create meaning based on their position in the world. Meaning can therefore be influenced by factors such as age, culture, past experience and so on. Likewise, Spinelli (2007) argued that individuals can not be understood in isolation, but instead should be considered in terms of their interrelatedness to the world and others. Since relatedness is always fluid, Spinelli (2007) suggests that there is no objective reality. Consequently individuals attempt to make meaning through their 'worldview', which is a structural focus that humans impose on the world in order to make sense of their reality. A theory that has greatly influenced the existential concept of relatedness is Buber's (1970) notion of "I-it" and "I-Thou" relationships, where an object can either be experienced as separate to ones experience, or approached as an inter-relational co-subject inseparable from the experiencer. Buber (1970) suggested that having an "I-it" relationship implies asymmetry and promotes a master-slave relationship. Conversely, "I-thou" relationships lead to the 'other' being treated an I and therefore does not imply a power imbalance. Buber (1970) proposed that our "selves" and community emerge from "I-Thou" relationships. Thus Buber (1970) rejected the Western culture of "I-it", which he felt can lead to isolation and dehumanisation, and advocated the person as an integral part of the relationship between other people and the world.

1.2.3 Religion and spirituality as sources of meaning

Meaning can be derived from a sense of transcendence and a belief in something bigger than oneself which is often framed in terms of religion and/or spirituality (Yalom, 1980). Kierkegaard's (1845; 1988) early existential ideas relied heavily on

Christian concepts. He proposed three stages to human development as individuals struggled to accept their freedom. The first phase, termed the aesthetic stage, is where people enjoy freedom only concerned with everyday activities (Kierkegaard, 1843; 1988). Then follows the ethical stage where people begin to form a direction in life and acknowledge the forces of good and evil (Kierkegaard, 1843; 1988). Finally the highest stage of human existence is the religious stage involving a commitment and relation to God (Kierkegaard, 1845; 1988). However Kierkegaard (1844; 1985) maintained that this commitment required a 'leap of faith' into the unknown since no one can be sure of God's existence. Kierkegaard's (1845; 1988) inclusion of religion was contentious and later existential theory relied less heavily on religious influence, with some authors taking an extreme stance including denying the existence of a God and claiming life is inherently meaningless.

Nietzsche (1885; 1961) famously claimed that God is dead, and concluded that all meanings are ideas that we have imposed on the world rather than a discovery of the natural meaning of the universe. Therefore without the guidelines of religion we must create our own path to realise our potential. Thus according to Nietzsche (1885; 1961) humans must recognise their freedom and choice and face the anxiety that comes from living with uncertainty. Sartre (1943; 1956) also firmly held onto the belief that the world is entirely meaninglessness; *it is meaningless that we are born; it is meaningless that we die"* (1943; 1956; p.547). However many philosophers have criticised this approach since it lacks any motivation towards ethical living (Yalom, 1980). In contrast, Frankl (1962) maintained that there is an objective meaning out there to be discovered. Although man must discover his own personal meaning, Frankl (1962) claimed that there is a 'supermeaning', which is incomprehensible to the limited intellectual capabilities of humans. It is clear that Frankl (1962) is making reference to God as the ultimate order, since he argues that those who have religious affiliations have an even stronger meaning in life in the face of suffering and death. Therefore for Frankl (1962) the human struggle is not with the meaninglessness of life, as proposed by authors such as Nietzsche (1885; 1961) and Sartre (1943; 1956), but with not being able to comprehend the ultimate meaning which would provide the answer to human suffering.

Therefore there appears to be two types of meaning in existential literature; personal meaning and ultimate or religious meaning, which Yalom (1980) termed terrestrial and cosmic meaning respectively. Cosmic meaning refers to a structure beyond the individual, which within the Western world is often attributed to the Judaic Christian tradition that there is some sort of divine order to the universe. Religion is often referred to as the ultimate meaning (Pargament, 1997), and individuals can be comforted by the notion of a divine presence and the immortal soul. Religion provides individuals with a clear role, goal and set of guidelines which leaves no doubt as to how one should live their life (Yalom, 1980). However, in recent times science and the questioning of an objective reality has made it more difficult for individuals to accept a cosmic meaning system. Authors such as Postman (1996) have claimed that man created God due to an inherent need to transcend our biological frailty. Furthermore, the collapse of socialist and communist ideals has meant that society places greater value on the individual rather than man as a whole (Walter, 2002). Consequently, a greater emphasis has been placed on terrestrial meaning where individuals must discover their own reason for living. Some individuals have referred to this as being "spiritual" without subscribing to an organised religion (McFadden, 2000). However what exactly spirituality means with the existential literature is not clear. Some existential authors, (e.g. Reker and Wong, 1988) claim spirituality is the process of transcending the self to find meaning. This is also how Frankl (1962) uses the word; *"people forgot that often it is just an exceptionally difficult situation that gives man the opportunity to grow spiritually beyond himself"* (Frankl, 1992; p.80). Similarly, van Deurzen (2002) suggested that there is a spiritual dimension to human existence, which refers to how we make sense of the world and create meaning. However the concept has not been comprehensively explored in the existential literature and therefore it is not clear if spirituality is cosmic meaning, terrestrial meaning or something completely different.

1.3.1 Finding meaning when faced with advanced cancer

Existential theorists suggest that individuals experience anxiety when we become aware of our certain death (e.g. van Deurzen, 2002). Heidegger (1927; 1962) defined Dasein as a being-towards-death since we are always projecting to the future. When we acknowledge the limitations of our existence we can live authentically and take responsibility to make life meaningful. To be in denial about death is to live inauthentically (Heidegger,1962). When faced with advanced cancer individuals are forced to recognise the reality of their own death and as a result meaning is no longer a vague or inconsequential concept but a question that needs to be answered with a sense of urgency (Breitbart, Gobson, Poppito and Berg, 2004). Existential distress can occur when individuals with cancer struggle to find meaning as they hurtle towards the reality of their death (Breitbart et al., 2004).

Existential concerns are therefore extremely important in the care of people with advanced cancer. However, even though existential psychotherapy is appropriate for individuals with cancer, surprisingly little has been written about this topic (Spira, 2000). Following the assertion that individuals can find meaning right up until the last moment of life (Frankl, 1962), it is argued that finding meaning whilst dying can liberate the person from being a passive victim of circumstance. Discovering the reason for being alive can help individuals come to terms with their past, present and future and bear the burden of suffering (Breitbart et al., 2004). Yalom (1980) noted from his own clinical work the frequency with which people with terminal illnesses reported reprioritising their life, feeling free and having less interpersonal fears. Yalom (1980) concluded that individuals who are facing death with a sense of purpose are better able to live fuller lives with zest and passion. This is supported by anecdotal evidence such as Professor Schwartz in the international bestseller *Tuesdays with Morrie* (Albom, 1997). Professor Schwartz considered his enthusiasm for life to be a result of his determination to keep teaching others about his philosophy in life. In addition to this clinical evidence highlights the importance of meaning in life for people with severe illness. For example Brady, Peterman, Fitchett, Mo and Cella

(1999) found patients with a high degree of meaning can get more enjoyment out of life even if their pain rating is severe. Rodin and Langer, (1977) found even the simple task of caring for a plant increased the quality of life for nursing home residents both psychologically and physically.

1.3.2 A meaning-centred group

Despite the theory that individuals could benefits from gaining meaning in their lives, Greenstein and Breitbart (2000) noted that there is only a small amount of literature on psychotherapeutic strategies for palliative care patients. In response they started a meaning centred group in the US aimed at increasing the sense of meaning and purpose in life for individuals with a terminal illness (Greenstein and Breitbart, 2000). The course, an eight week manual-based treatment, was heavily based on the work of Viktor Frankl's (1962) *Man's Search for Meaning*. The focus was on both learning and support, with the hope that attaining purpose and meaning in life would reduce the amount of distress experienced by the participants (Greenstein and Breitbart, 2000).

Before the group started all members were asked to read Frankl's (1962) work. Over the weeks of the course there were a number of exercises, including making a list of things in their life which gave them meaning and purpose, naming three things for which they were are responsible, creating the story of their lives, and what their hopes were for the future (Greenstein and Breitbart, 2000). Greenstein (2000) noted in an article on the themes that arose from the group that love and relationships with others was put at the top of the list of sources of meaning. Also the importance of connectedness to others (not just family members) was constant topic throughout the meetings. It was found that most participants did not think about death but instead focused on day-to-day tasks. Greenstein (2000) found participants spontaneously reframed their illness and the majority of changes caused by the cancer were viewed to be positive. As hypothesised by Frankl (1962) participants differed in their attitudes. These differences included intensification of love and support, more social openness and a general sense of personal growth.

Breitbart and Heller (2001) later analysed quantitative data from the group which was gathered at the beginning of the group and three months later using the FACIT scale, which measures sociodemographic, medical and psychological variables (Cella, 1997). The results indicated that in both meaning-centred groups and in support groups, patients have less psychological distress, less depression, and more social support. The meaning-centred group also showed an enhanced spiritual well-being and sense of meaning, as well as less hopelessness and less desire for death (Breitbart and Heller, 2001). Furthermore, self reported evidence suggested that the group continued showing a sense of meaning and purpose in life as participants carried on after the group with their projects, such as film making, gardening and cooking. Breitbart and Heller (2001) therefore concluded that the group had been helpful in creating feelings of connectedness between people and within individuals whilst exploring issues that are meaningful and important in this stage of their life.

1.3.3 Therapy for individuals with advanced cancer

Lockett (2009) wrote about her experience of working with people with cancer, which she considered in terms of Yalom's (1980) four existentials (death, freedom, isolation and meaning). When considering death with clients with cancer, Lockett (2009) found that individuals focus on their temporal limits. Consequently therapy can aid making plans for future and thinking about the life that has gone. Individuals may find it helpful to prepare for death and make practical decisions about treatment options. In terms of freedom, Lockett (2009) argues that cancer attack bodies, identity, a person's sense of self-worth, invulnerability, security and belief system. However from the "abyss" new structure can emerge allowing the person to gain a better sense of who they are. Therapy can help regain identity, gain a sense of self and make realistic choices with cancer diagnosis.

Feeling isolated can be a consequence of considering the ultimately meaningless and contingent nature of the world. Lockett (2009) suggests that therapy with individuals with cancer can therefore focus on tapping into the client's resourcefulness and helping them chose how they want to be in the world. This can involve reviewing and building new relationships. The final existential, meaning, is particularly important for individuals with cancer (Lockett, 2009). People will often search for the answer to

"why me?" without finding a satisfactory result. Lockett (2009) proposes that therapy therefore concentrates on helping the client accept the chaotic nature of the world. This hopefully helps the person discover what has meaning lives, what is trivial and what they want to do more of. Goals can be reprioritised and clients can seek pleasure in small everyday tasks.

1.3.4 Spirituality as meaning for individuals with advanced cancer

Given that meaning is an important concept for palliative care patients what exactly constitutes meaning? As well as Frankl's (1962) definitions, meaning has been equated with purpose (Crumbaugh and Maholick, 1964), goal directedness (Ryff and Singer, 1998) a sense of coherence (Reker and Wong, 1988) an awareness of the value, fragility and preciousness of life (Bower, Kemeny, Taylor and Fahey, 2003) or the personal significance of a particular circumstance (O'Connor, Wicker and Germino, 1990). Meaning has also been related to feelings of harmony and integration (Paloutzian and Ellison 1982) and the belief that humans fit into an overall pattern that exists superior to the individual (Yalom, 1980). Research into this construct has lead to a number of measures claiming to tap into meaning, such as The Purpose in Life Test (PIL; Crumbaugh and Maholick, 1964), the Life Regard Index (LRI; Battista and Almond, 1973) or the Sense of Coherence Scale (Antonovsky, 1987). A more popular measure recently has been the Meaning in Life Scale devised by Jim, Purnell, Richardson, Golden-Kreutz and Andersen (2006). This scale is based on the belief that meaning in life comes from a sense of purpose, coherence and fulfilment in life. The scale involves four facets including; harmony and peace, life perspective, purpose and goals, beliefs and spirituality.

One important facet of meaning that is repeatedly mentioned in the palliative care literature is spirituality. For example Griffiths, Wagstaff and Brunas-Wagstaff (2002) elicited the concerns of people with advanced cancer and found relationships and spiritual or religious meaning was important in their lives at this point. King, Speck and Thomas (1995) found that 71% of people who entered their acute hospital study had an important spiritual belief even though many did not claim to be religious. Kearney and Mount (2000) went even further claiming that spiritual issues lie at the very centre of the existential crisis that is terminal illness. Spiritual needs are often

cited as high on the list of concerns for people with a terminal illness. For example Moadel, Morgan, Fatone et al. (1999) interviewed 248 participants with cancer and found the most important needs were overcoming fears, finding hope, finding spiritual resources and having someone to talk about finding peace, the meaning of life and death and dying.

The importance of spirituality is also indicated by the term "spiritual pain" (Saunders, 1988) which is used when individuals are struggling with existential questions. Kearney (2000) claimed that spiritual pain derives from the deep anxiety associated with the prospect of the end of one's existence and subsequent loss of meaning and purpose in life. Mako, Galek, and Poppito (2006) explored the concept of spiritual pain further to understand the difference between spiritual pain and emotional and physical pain. Fifty-seven individuals with advanced cancer who had been admitted to the hospice were interviewed by a chaplain. The chaplain defined spiritual pain as "a pain deep in your being that is not physical" and asked individuals to describe what spiritual pain was to them, if they were experiencing it now, and to rate the level of intensity on an 11 point likert scale. The findings revealed that 96% of people interviewed considered themselves to have had spiritual pain at some point in their lives, 48% of the individuals felt their spiritual pain was intrapsychic (e.g. suffering from despair, loss, regret or anxiety), 38% felt this was with associated with the divine (e.g. feeling abandoned by God, being without faith, and/or religious community), and 13% thought their spiritual pain was in relation to interpersonal dimension (e.g. feeling unwanted by family members, feeling disconnected from others). The authors concluded that spiritual pain is different to depression and that healthcare professionals should explore possible language used to distinguish spiritual pain from physical or emotional pain. However the study does not make it clear how spiritual pain is different from emotional pain, particularly since the research is based around an extremely vague definition of spiritual pain.

1.4 What is spirituality?

1.4.1 Definition of spirituality

Clearly "spiritual" issues are important to this patient group, and indeed NICE (2004) guidelines recommend that health and social care professionals regularly assess spiritual issues - but what exactly are they referring to? The definitions of spirituality vary hugely and researchers are yet to find a consensus, as acknowledged at the beginning of every paper discussing the topic (Walter, 1997). The following section gives an overview of the different definitions of spirituality, although it is not intended to be an exhaustive list. Instead the purpose is to draw attention to the variety of conceptualisations of spirituality. When reviewing the literature there were not any noticeable differences in the definitions of spirituality across Western countries. The only significant point of difference was in the few studies in Eastern countries, which made reference to specific ideas derived from Eastern culture. For example the term "spirit" in Western culture is derived from the Latin root for breath, whereas "spirit" in Chinese culture means *chi*, the energy with which heaven, the earth, the universe and nature is filled (Chien, 1994). Watson (1988) argues that the Chinese are more spiritually evolved than Westerners due to their long history of spiritual concerns and capacity for higher levels of consciousness. These are considered further in the studies examined in the literature review.

In a review of the spirituality literature, Chiu, Emblem, Hofwegen, et al. (2004) found most researchers define spirituality within the existential dimension. Many authors refer to spirituality as an individual experience or a way of being which is associated with the idea of a personal journey (Chiu et al., 2004). In UK and US health care and nursing textbooks spirituality is presented as the human search for meaning (Walter, 2002). Benzein, Norberg and Savemen (1998) consider spirituality as a person's need to answer the big questions in life and Sulmasy (2002) claimed that although not everyone has a religion, anyone who is seeking ultimate meaning has spirituality. Furthermore, a loss of spirituality has been regarded as a loss of meaning and purpose in life (McCormick, Holder, Westel, and Cawthon, 2001).

Spirituality has also been discussed as a connectedness with the self, others, nature of a Higher being (e.g. Burkhardt, 1993). One of the greatest disagreements in defining the term spirituality is whether it includes a divine or higher being, and if so to what extent is the concept distinct from religion (Wulff, 1997)? The etymology of the word spirit is Latin root *spiritis* meaning breath, courage, vigour, the soul, life or from *spirare*, to blow or to breathe (McKechnie, 1983). However later the word became affiliated with Christianity, with *spiritualis* meaning "of or concerning the church" (attested from 1338; Chambers, 1999). This is especially confused by the fact that all religious people would regard themselves as spiritual (Grey, 1994); so what does it mean to say you are spiritual without being religious? It is clear that many authors appear to still have a significant Judaic-Christian influence on their definition of spirituality but minus the rigidity of organised religion. For example Brady et al. (1999) claim spirituality involves faith in a higher being, though not necessarily God and not necessarily achieved through rituals or beliefs. Robinson (2008) defined religion as a system of faith and practice expressing a particular spirituality which is based on awareness of the ultimate other or God. The distinction between spirituality and religion is further confused by authors that use the words interchangeably (Zinnbauer and Pargament, 2005).

Spirituality has been considerd a relationship with the self leading to an awareness of the inner dimensions (e.g. Chiu et al., 2000). Swinton (2004) defines spirituality as a dimension of humanness that is unquantifiable, mysterious and individual. Heidegger (1927; 1962) claimed that spirituality is a psychic phenomenon which can only be explored through reaching the inner recesses of the mind. This relates to the idea of living life authentically with commitment and openness (Hall, 1998). Drawing on inner strength and resources (e.g. Bowden, 1998) and striving for self-actualisation (e.g. Standard, Sandhu and Painter, 2000) are also common themes in the literature relating spirituality to a connection with the self (Chiu et al., 2004).

According to Chiu et al. (2000), spirituality defined as a connection with others involves sharing and helping others. Hasse Britt, Coward, Leidy, and Penn (1992) viewed spiritual connectedness as richer than social support due to its meaningful and significant relationship with another person. Drawing on Buber's (1970) work, Eliason, Hanley and Leventis (2000) regarded spirituality as the unifying factor in the

"I-Thou" experience, allowing us to transcend the body and connect with others. Alternatively spirituality has been defined as a connection with the universe or eternal occurrence. According to this theory, man is a transient being like the ocean or the sky, and when we die we will continue to exist but in a different form (Karasu, 2003). Thus individuals are immortal as part of the life cycle, which brings about feelings of importance and purpose (Shaw, 2005). Spirituality has also been discussed as an experience with music, love, beauty or nature associated with the idea of an expansion of the self (Pulchalski and Romer 2000). Thus the emphasis is not on experience with a higher power or being, but an experience within the material world.

Other authors have substituted the idea of a higher being or power for the notion of transcending the self. As discussed earlier this is also how Frankl (1962) regards spirituality. Puchalski and Romer (2000) define spirituality as *"that which allows a person to experience transcendent meaning in life"* (p. 129) and Wright (2002) refers to spirituality as transcending the here and now by reaching beyond and within the self to address the big questions of life. Reed (1991) described this process as expanding beyond the boundaries of situational or physical limitations. Spirituality as transcendence can also involve existing beyond space and time (e.g. King, Speck and Thomas, 1999). However Chiu et al. (2000) found spiritual transcendence to be a developmental process leading to the liberation of suffering and the acknowledgement of life and death.

Due to difficulties with defining spirituality, many authors have now begun to define "spiritual well-being" instead. For example Lin (2003) reviewed the literature using the words 'psychological', 'coping', 'adjustment', 'spirituality', 'meaning' and 'hope'. They concluded that spiritual well-being involves self awareness, coping and adjusting to stress, relationship and connectedness with others, sense of faith, sense of empowerment and confidence and living with meaning and hope. Westgate (1996) also surveyed the literature and found four dimensions of spiritual wellness; meaning in life, intrinsic values, transcendence, and community of shared values and shared support. However it seems that these definitions are focusing more on how people 'cope' with illness rather than what spirituality means for a person. It would therefore be unwise to conclude that spiritual well-being and spirituality are the same concept

particularly since there is little qualitative data on the meaning of "spiritual well-being".

Liberating the concept of spirituality from the structure and rigidity of religion has allowed a broader application of the term. However, the trade-off is that the notion of spirituality is difficult to articulate since it evades precise language, symbols, narratives and beliefs (McFadden 2000). In response researchers have proposed overly broad definitions of spirituality to encompass all perspectives (e.g. Emblen, 1992). But as Walter (1994) argues is such a broad and ambiguous concept is even meaningful? Alternatively some authors, such as Byrne (2007) have argued that spirituality as a concept has become resistant to language and therefore it is impossible to define. Consequently, researchers have begun to view spirituality as part of the person's personal experience which is as unique as the individual (Sinclair, Pereira and Raffin, 2006). McGrath (2002) considered this the only way to understand spirituality: *"conceptually, spirituality cannot be understood as an independent entity to be measured and recorded. Researchers need to be open to the plethora of ways that individuals construct meaning.."* (McGrath, 2002; p. 183). Keighley (1997) regarded spiritual awareness as a fluid process of interrelatedness with the world and others. Thus each one of us will interpret spirituality differently depending on our culture, beliefs, experiences and social background.

Coleman (2004) has argued that we could reduce the elusiveness of spirituality by recognising it as a cluster concept, like health. Therefore the term would refer to a wide range of human experience such as meaning, coherence and relatedness rather than a clearly definable and measurable entity. The National Association of Health Authorities and Trusts' (1996) guide to spiritual care states that there is a potentially spiritual dimension to everyone and the Royal College of Nursing (1993) guidelines for palliative care also consider that every person has a spiritual dimension. But perhaps spirituality is just not relevant to everyone which is why the research has become confused as researchers label a number of phenomena under the term "spirituality". Walter (2002) suggests there is no universal spirituality but instead proposes fours types of discourse about spirituality and religion: formal religion; folk religion (e.g. spirituality, new age, feminism); explicit secularism (e.g. humanism, atheism); and implicit secularism (e.g. no formal belief systems). This model

recognises that people can be either implicitly or explicitly spiritual and suggests that spiritual terminology should not be imposed on people and instead only used in people who embrace spiritual discourse: *"we could see all four boxes in Figure 1* [i.e. the four categories of discourse] *as ways humans are given, or construct meaning; but to see them all as spiritual, which most writing on spirituality in health care does, when only some of those in only one or at most two boxes use that terminology, is poor social science and poor pastoral care"* (Walter, 2002; p.138). Therefore from reviewing the literature it can be seen that there are many unanswered questions about what spirituality is, if it is possible to define it and to whom it may be applicable.

1.4.2 Spiritual care

Much of the nursing literature has focused on the idea of spiritual care rather than trying to define spirituality. Many patients have indicated a need to receive spiritual care from their physicians (Breitbart et al., 2004) leading to the suggestion of a biopsychosocial-spiritual model of care (Sulmasy, 2002). Attending to the spiritual dimension is assumed to move beyond pain management to focus on holistic healing (Bryson, 2004). However despite individuals' requests for care in this area, physicians are often reluctant to discuss spiritual issues with their patients (King and Bushwick, 1994) and Sulmasy (2006) found physicians can be afraid to probe too far or upset the patient. Perhaps this fear comes from not understanding what spiritual care involves and how they might be able to provide it.

The hospice movement is rooted in Christianity but has evolved over the years to accommodate a multifaith society. Dame Cicely Saunders was a prominent figure in emphasising the importance of palliative care and drew on Logotherapy (Frankl 1962) to promote spirituality as a search for meaning and purpose (Walter, 1997). However Saunders originally came from an evangelical background which meant the early hospice movement was notably influenced by Christianity (Walter, 1997). With so many definitions of spirituality in the current literature, how do nurses execute spiritual care, and how does this differ from other kinds of care? Give the broadness of the concept it seems that spiritual care is likely to infiltrate all aspects of nursing.

Wright (2002) conducted a phenomenological study with sixteen stakeholders who identified themselves to the researchers as being 'first hand at giving people spiritual care'. The participants discussed spiritual care as affirms the value of each individual, and involves empathy, non- judgemental love and affirming the worth of each person in the eyes of God. Wright (2002) concluded that spiritual care was about seeing the person as unique and discovering their purpose in life, values and religious beliefs. However Wright (2002) acknowledged the confusion between spiritual care and religion and called for a broader definition of the spiritual domain. Carroll (2001) also conducted a phenomenological study exploring nurses' definition of spiritual care. Analysis showed the nurses considered the idea that every individual being unique was a central feature of spiritual care, and that spirituality was therefore seen as the inner self. Spiritual care in this context involved getting in touch with feelings, thoughts and connectedness with other people, God and the universe. However, the nurses' descriptions were clearly influenced by their own beliefs, since those from a Christian background regarded spiritual care as more relevant to a relationship with God. Therefore it is not clear what spiritual care may involve in the absence of religion.

White (2000) conducted a discussion group to aid healthcare professionals explore the notion of spiritual care. They met together to discuss issues and articles, firstly decided by the researcher and later themselves. They concluded that spirituality could be developed in different ways, such as through relationships, creativity and art, social concern and meditation, as well as through religious and non-religious beliefs and values. The participants recognised that since spirituality is hard to define, it is easy to neglect this aspect of patient care, particularly in individuals without a religious affiliation. They considered the use of metaphor, for example talking about journeys, could be helpful for expressing spiritual concepts that are not accessible through concrete language. White (2000) found that the experience of the discussion group ensured that participants were better able to identify spiritual concerns and more confident in being able to discuss these issues. The participants were reluctant to develop a formal assessment tool, which they felt would miss the purpose of spiritual care if it became another medicalised task of healthcare. They felt routine questions to open the conversation with patients could be useful, and considered activities such as complementary therapy, creative writing, and arts groups to be helpful in

facilitating spiritual care. The group concluded that spiritual care is not something that can be summarised, or fulfilled in a short space of time but an aspect of care that takes time and creativity to explore.

1.4.3 Assessing spirituality

Despite a lack of consensus over the definition there has still been a wealth of literature attempting to find a scale to measure spirituality. In agreement with White (2000), Jones (2004) found that healthcare professionals prefer to use an intuitive approach to assess spirituality in patients. However the introduction of NICE (2004) guidelines recommending the importance of spiritual assessment has lead to pressure to develop a standardised measure to ensure that all medical staff are doing this as part of their routine healthcare (Walter, 1997).

Chiu (2004) found thirty-one research instruments in a review of the literature on spirituality, of which twenty-eight claimed to be an exclusive measure of spiritual attributes. Quality of life instruments are often used as general measures with a subscale on spirituality. For example the WHOQOL included a spirituality subscale following reports from focus groups around the world that spirituality was an important component of their quality of life (The WHOQOL group 1995). However, research looking specifically at the effects of spirituality on health tend to use scales exclusively measuring spirituality.

A more specific scale that is growing in popularity is the Functional Assessment of Chronic Illness – Spiritual Well Being (FACIT-Sp; Peterman, Fitchett, Brady, et al., 2005). Devised from cancer patients, psychotherapists, and hospital chaplains, the scale claims to measure spiritual well-being with questions about meaning in life, harmony, peacefulness and a sense of drawing strength and comfort from one's faith. The scale was validated and two factors were discovered in the scale; meaning and peace, including items such as "I have a reason for living" (eight items), and faith measured by questions such as "my illness has strengthened my faith/ spiritual beliefs" (four items) (Peterman et al., 2005). Later Canada, Murphy, Fitchett et al. (2008) discovered in a study of females in remission from breast cancer that meaning and peace were actually two separate dimensions. However the sample for the study

was limited, since the interviewed mainly young, married women who were from the "Bible belt" region of America. It is important to note that although the FACIT-Sp (Peterman et al., 2005) is used in spirituality research, it only claims to measure "spiritual well-being", therefore any conclusions made about the nature of spirituality should be made with caution. Also the FACIT-Sp (Peterman et al., 2005) has been criticised for overlapping with measures of depression (Nelson, Rosenfield, Breitbart and Galietta, 2002). Therefore whether this measure is tapping into a unique dimension of spirituality is yet to be concluded.

King, Jones, Low, Walker et al. (2006) argued that most spirituality assessments are based on North-American Judeo-Christian concepts and thus do not accommodate people from other religions. In response they attempted to expand the measurement of spiritual beliefs beyond a religious context by using qualitative data from palliative care patients, GP patients and a sample of well populations. Individual interviews and focus groups were conducted asking participants: 'What does your life mean to you?'. 'What are your beliefs?', 'What makes your life worthwhile?', 'Do you have any spiritual understanding of your life?' and 'How do you express your spiritual beliefs?'. The principle themes from the qualitative data included a search for meaning in their world, relationships with others and personal circumstances, ideas on God, religion, meditation, prayer and life after death, and their reactions to the world around them, particularly to the beauty or grandeur of nature. The Beliefs and Values Questionnaire was then developed from the qualitative data (King et al., 2006). The authors avoided using the term "spiritual" and instead used the language of the concepts that arose from the data to name the scale. However, although the name "The Beliefs and Values Scale" was considered the most appropriate terminology, King et al. (2006) still consider it a measure of "spiritual belief". Furthermore King, Jones, Low et al. (2005) acknowledge that during the process of their focus groups, many people struggled to find the words to express "spirituality". This was particularly evident for those who had no religious affiliation. Nevertheless, they claim that their twenty-item questionnaire has captured the concept of spirituality for religious and non-religious people from all backgrounds and cultures.

Given that the definitions of spirituality are so broad and varied, it seems somewhat ambitious to be able to capture the concept within a questionnaire. The idea of

exploring spirituality and spiritual care was to move away from the medical model and towards a more holistic method of care. However the pressures of NICE guidelines and the threat of audits have lead to a race to get a tangible measure of spirituality (Walter, 1997). Assessing spirituality in a quantifiable manner appears to defeat the object of the exercise, risking it becoming just another part of emotional/physical care (Walter, 1997). Sulmasy (2006) argues that spirituality cannot be reduced into categories like a medical assessment. Asking questions to be answered on a likert scale prevents the person from describing their own journey and instead forces them to conform to the answers offered. Thus questionnaires do not allow exploration of the intricacies of such a complex concept, and instead produce a superficial overview (Polit and Hungler, 1995). Stanworth (2004) argues that in order to attend to the spiritual needs of an individual it is essential to appreciate the poetic function of language. Individuals use symbols and metaphors to draw attention to aspects of their experience which would be lost using a questionnaire. This therefore calls into question whether spirituality can be assessed scientifically (Bash, 2004). Byrne (2007) suggests that spiritual assessment should at best only be used as a heuristic: *"patient narratives or stories are believed to be efficient living assessment tools, bringing connection often spontaneously in conversation or at the time of assessments. The experienced professional will observe and actively listen to stories and dialogue, which can allow a spontaneous assessment. Tools, however, are helpful to the less experienced"*. (Byrne, 2007; p.120).

1.4.4 Research on spirituality and palliative care

Despite the debatable validity of assessing spirituality through questionnaires, there has been a rapid increase in the number of studies exploring the physical and psychological benefits of spirituality using these measures. The wealth of this literature comes from palliative care research which has seen a 600% increase in this type of publication in a ten year period (Stefanek, McDonald and Hess, 2005). The papers cover all aspects of well-being including quality of life, depression, end of life despair, desire for hastened death, pain and death distress in relation to spirituality. The following studies are a sample of the type of research being published in recent times.

There appears to be a consensus in the literature that spirituality is positively correlated with overall well-being. For example Brady et al. (1999) found significant associations between quality of life and the FACIT-Sp (Peterman et al., 2005) in participants with cancer or HIV. They found spirituality was a unique measure since it continued to predict quality of life when controlling for physical well-being, emotional well-being and social well being. They found similar but smaller results with tolerance of pain, suggesting that those who have meaning in life are better able to cope with physical symptoms. Chibnall (2002) looked at death distress (defined as death-related fear, obssessiveness, nervousness and arousal) and death depression (defined as death -related feelings of sadness, dread, meaninglessness and lethargy) in patients with a terminal illness. Using the Spiritual Well-Being Scale (Paloutzian and Ellison 1982), which measures spiritual well-being vertically (i.e. in relation to higher being or God) and horizontally (i.e. existential meaning and purpose in life) they found spiritual well-being on both dimensions was negatively correlated to death distress. Other variables for predicting death distress were physical symptom severity, depression, patient perception of communications with their physician around psycho-spiritual needs and decision making.

Meravigilia (2004) explored the effects of spirituality on the well-being of people with lung cancer. Participants were given the Life Attitude Profile – Revised (LAP-R; Reker, 1992) which measures meaning, purpose in life and motivation to find meaning, an adapted prayer scale (Meraviglia, 2002) as well as measures looking at symptom distress and general well-being. They found that people who reported more meaning in life had better psychological well-being and as meaning in life increased, their symptom distress decreased. Prayer was also positively correlated with well-being. Meravigilia (2004) concluded that spiritual meaning in life and prayers have positive effects on psychological and physical responses to lung cancer. However, it is unclear which questionnaire, if any, measures "spirituality". It appears that Meravigilia (2004) makes a leap from analysing the effects of "meaning" in the findings to calling this "spiritual meaning" in the conclusion. Furthermore the fact that the sample was mostly Christian is likely to have biased the results.

Nelson (2002) used the FACIT-Sp (Cella, 1997) to explore the effect of spirituality on depression in terminally ill oncology and HIV patients. They also measured religion

using the following questions: do you consider yourself a religious person (very much/slightly/not at all) and how often do you attend religious services (regularly/sometimes/never). The results showed a negative correlation with depression and spirituality (as measured by the FACIT-Sp; Cella, 1997), whereas religion had a negligible or even small positive association with depression. The strong negative correlation between the meaning/ peace subscale (which corresponds to the existential aspects of spirituality) and depression lead the authors to conclude that the benefits of spirituality may be related to one's ability to search for strength and meaning. However, as with Meravigilia (2004) the vast majority of the participants were religious (only eight out of one hundred and sixty-two reported having no religion), which makes it hard to distinguish between religion and spirituality. Also, as the authors themselves acknowledge, their measure of religiosity was very limited for a construct that is presumably more complex than then two questions they used.

1.4.5 Theories relating to spirituality

There is a strong emphasis on cognitive models of coping within the spirituality literature. If the findings are related back to a theoretical model, invariably the framework chosen is Park and Folkman (1997) theory of global and situational meaning. Global meaning relates to peoples generalised expectations, beliefs and assumptions about the world generated over their lifespan. Thus global meaning includes an individual's beliefs about the order of the universe, as well as their purpose and goals (Park and Folkman, 1997). Religion and spirituality are often cited as primary contributors to global meaning since these beliefs can offer a structure to interpret the world (Jim et al., 2006). Situational meaning on the other hand refers to the interaction of the person's global beliefs with the immediate situation. Therefore the product of this interaction influences how a person copes with a situation. According to this theory if a person finds congruence between global and situational meaning they are less likely to feel stressed than in a circumstance in which the person's situation meaning conflicts with their global meaning. Therefore the challenge after a traumatic experience like a cancer diagnosis is to find congruence between global and situational meaning, which is considered an adjustment or coping style (Jim et al., 2006). Thus according to this theory spiritual coping is the use of

spiritual or religious beliefs to reduce the emotional distress caused by loss or change (Koenig, McCulloch and Larson, 2001).

Pargament's (1997) work on religious coping is considered seminal in the cognitive conceptualisation of religion and spirituality (Gall, Kristjansson, Charbonneau, and Florak, 2009). Pargament (1997) described three types of religious coping mechanisms for dealing with incongruence between global and situational meaning which has been used extensively in the literature looking at spirituality. The coping styles are: collaborative, in which people co-operate with God to deal with stressful events; deferring in which people leave everything to God; and self-directed, where people do not rely on God and deal with the situation themselves. The resources activated in this time, according to Pargament (1997) are influenced by the degree of religious or spiritual beliefs in one's cognitive schema and the embeddedness of this schema for the individual. Studies have found support for this theory, such as Jacobsen, Luckhaupt, DeLaney and Tsevat (2006) who observed that people using religious or spiritual beliefs to cope with HIV could be categorised into deferring believers, collaborative believers, spiritual/religious seekers and people who use self directing behaviour.

Pargament, Smith, Koenig and Perez (1998) later went on to distinguish between "positive" and "negative" spiritual coping styles. Positive spiritual coping refers to a secure relationship with God, a belief in a meaning in life, and a spiritual connectedness with others. Negative spiritual coping is considered a less secure relationship with God, an unsure view of the world and a religious struggle in the search for meaning (Pargament et al., 1998). Studies such as Boscaglia, Clark, Jobling and Quinn (2005) and Tarakeshwar, Vanderwerker, Paulk et al. (2006) have subsequently shown that negative spiritual coping is associated with greater depression and anxiety.

Pargament et al.'s (1998) theory is clearly heavily influenced by religion and so it is hard to extrapolate these findings to people who are spiritual without being religious. This seems to be leading to more confusion between the terms spirituality and religion in authors adopting this theory. For example Gall et al.'s (2009) study claimed to look at the role of spirituality in response to breast cancer. However the measures

used are clearly confounding the term spirituality and religion, as they measure the frequency of church attendance, the perceived importance of religion and the perceived importance of spirituality (measured on a 5 point likert scale). They found that women who were less spiritually/religiously involved prior to breast cancer experience more distress when they attempt to mobilise spiritual/religious coping mechanisms. However their confounding of the terms spiritual and religious calls into question what exactly they mean by spirituality.

1.4.6 Problems with spirituality literature

Research into spirituality is hindered by a lack of consensus over what the term "spirituality" actually incorporates. Chiu et al. (2004) found the majority of articles between 1990 and 2000 conceptualised spirituality in imprecise ways, often leaving the reader to deduce the meaning of the concept, even when spirituality was the main focus of the article. Many articles define spirituality in religious terms (Schnoll, Harlow and Brower, 2000) which is likely to be because religion is easier to conceptualise in terms of attendance at church, rituals and prayer (Hodges, 2002). Some articles even use the terms religion and spirituality interchangeably without acknowledging any difference between the two (Eliason, Hanley, and Leventis 2001). Sinclair, Pereira and Raffin (2006) argued that most definitions of spirituality are theoretical and opinion based preventing a standard definition of the term. Also the strong emphasis on coping models has lead to more research into "spiritual well-being" and "spiritual coping" which are then used to make conclusions about spirituality. Therefore are all the studies exploring the same phenomenon?

The validity of the measurements used is often questionable in spirituality research. Stefanek et al. (2005) noted that many studies use single item assessments or questions addressing only one aspect of religion or spirituality and Sinclair (2006) found that most papers had no mention of the validity of the measure they used. After reviewing the literature, Chiu et al. (2004) noted that the reliability was mentioned for only 23 of the 31 instruments used in the studies. Furthermore, the issue of social desirability has not been addressed reducing the reliability of such scales (Stefanek et al., 2005). Given the lack of clarity over what the term spirituality means it is not surprising that measures are varied and incomplete. Thus are these measures tapping

into something meaningful? Or are they overlapping with other dimensions such as well-being and quality of life (Moriera-Almeida and Koenig, 2006)?

A further methodological problem within the spirituality research is the lack of exploration into confounding variables. Thune Boyle, Stygall, Keshtgar and Newman (2006) argued that studies fail to control for variables such as stage of illness and perceived social support which may bias the results. Furthermore many studies involve small samples of mainly white people from Western Countries who consider themselves religious, limiting the generalisability of the findings (Chiu et al., 2004). Consequently all the meta-analyses of the spirituality literature have called for more rigorous research within the spirituality literature, and many have indicated more qualitative research is necessary before developing a standardised concept of spirituality (e.g. Sinclair, 2006).

1.4.7 Conclusion

Spirituality has been identified as important by both healthcare professionals and people with terminal illnesses, yet there are still many questions about what this concept means. The strong emphasis on spiritual coping appears to have missed a step in research since conclusions are being made about how spirituality helps people without actually deciding on what a universally accepted definition of spirituality means. Therefore before continuing with research in this area it would seem important to revisit what spirituality means for people with advanced cancer. This is summarised by McGrath (2004): *"this is an area of research where the cart has always been placed before the horse, because of the inherent contradiction of requiring definitional clarity for methodological rigour prior to an understanding of the notion of spirituality itself"* (p 227; McGrath, 2004). Therefore to explore spirituality in depth it seems appropriate to use qualitative methodology to allow participant's to use their own terminology and ideas without imposing any biases from the researcher. This would also give participants the opportunity to describe the interrelational qualities of spirituality which are not captured when using a questionnaire that assumes spirituality to be a tangible concept that can be separated from the individual.

Despite the 600% increase in spirituality literature, mainly in the field of palliative care (Stefanek et al., 2005), there is a distinct lack of qualitative research looking at the experience of spirituality and meaning-making at the end of life. Six articles were found claiming to investigate the experience of spirituality in individuals with cancer, only two of which were investigating people with advanced cancer. This finding in itself demonstrates the need for more research in this area. The following sections summarise the results; the first four papers studied people with cancer, and the last two recruited participants with advanced cancer.

1.5.1 Albaugh (2003): Spirituality and life-threatening illness: A phenomenological study

The purpose of Albaugh's (2003) study was to examine the lived experience of spirituality in individuals diagnosed with a life-threatening disease. Seven participants in Chicago with life threatening illnesses (not necessarily cancer) were asked "what is the lived experience of individuals who consider themselves spiritual, when they are faced with a life-threatening disease?". Spirituality was defined as "a personal belief in a higher power or being that guides life" and all participants recruited considered themselves to be Christian. Answers were analysed using Giorgi's (1985) method of phenomenology. Five themes were discovered: a sense of comfort from aspects of spiritual life, i.e. that God would see them through whatever the outcome; trust in God that he would provide them the means to get through whatever the outcome is; strength from spiritual beliefs through prayer or scripture; being blessed in many aspects of life; and meaning in life even if they did not understand what this was. As is a problem in much of the literature on spirituality, Albaugh (2003) attempted to explore the experience of spirituality using the term synonymously with religion. Consequently the themes identified were highly related to Christianity as a result of the participants' religious beliefs. Therefore it is not clear if the themes described in this paper are describing the experience of spirituality or religion.

1.5.2 Chiu, Clark and Daroszewski (2000) Lived experience of spirituality in Taiwanese women with breast cancer

This study used hermeneutic phenomenology (van Manen, 1990) to study the lived experience of spirituality in Taiwan. Women with various stages of breast cancer (stage I-IV) were asked questions such as: What is your everyday life experience with breast cancer? What is the meaning of this experience to you? And how does that relate to your spirituality? Seven women were Buddhist, two were Taoist, four were Christian and two had no religion.

Four themes and twelve subthemes were identified which manifested the women's spirituality. These themes were conceptualised under a meta-theme, which Chiu et al. (2000) termed *hsin*, which translates as 'mind and heart' (Chien, 2004). The experience of spirituality was seen as a unidirectional developmental process to a larger realm. Chiu et al. (2000) regarded spirituality as unique to the individual and culturally specific. Once the women were able to face their circumstances and live with what they encountered, Chiu et al. (2000) found that the women went through a process of transcendence where one connects with the self, others and God (or *t'ien*, meaning supreme ruler in heaven). Transcendence allowed spirituality to evolve to high-order wholes and connectedness, and suffering was a path to reach higher-order spirituality (Chiu et al., 2000).

This process was captured in four themes, which were found to be interwoven concepts. It appears that Chiu et al. (2000) regarded this journey as constituting spirituality, rather than the terminology of the participants. Firstly "lived reality" involved: living with encounters, taking full responsibility, and appreciating life, people and beloved things. "Creating meaning" was the second theme, which included: purpose and meaning in life; finding alternative ways of life; and religion. The third category was "Connectedness with self, others and God". This theme consisted of: relationship with self; relationship with others; relationship with others (especially family); relationship with God/deity/*t'ien*. The final theme of spirituality was "Transcendence" which was addressed either implicitly or explicitly. Transcendence involved: suffering as the path to spirituality, liberation from the world,

opening to life and death, and healing experience when the mind and *hsin* come back into balance and you experience the present moment.

Chiu et al. (2000) concluded that spirituality should be understood as a pattern of meaning connectedness and transcendence in contrast to Western literature which is too involved in the Cartesian dichotomy between the body and soul. Consequently, Chiu et al. (2000) argues that spirituality should not be dissected but instead considered a process which is evolving towards wholeness. Chiu et al. (2004) noted that when asked about specific questions incorporating the term spirituality, the participants made reference to religion. Furthermore although two of the participants regarded themselves as non-religious, they did still believe in *t'ien*. Therefore as found with previous studies, these participants are likely to conceptualise spirituality through a religious framework because of their beliefs. Also it would be unwise to use this study to generalise to all cultures, as the responses are clearly influenced by Chinese beliefs. It is therefore important to study the experience of spirituality across many cultures.

1.5.3 McGrath (2004): Reflections on serious illness as spiritual journey by survivors of haematological malignancies.

McGrath (2004) attempted to look at the language of a secular spiritual journey rather than relying on a conventional theological framework. The study took place in Australia and used a phenomenological approach to look at the spiritual journey in twelve people in remission from haematological malignancy. Participants who regarded themselves as spiritual but not necessarily religious were asked to describe in their own words how their illness had changed the way they viewed the world and what they believed to be important from being diagnosed to the present day. Many individuals acknowledged that facing death was a significant instigating factor to reviewing their meaning of life. Themes of fear, lack of choice and desire to live were all cited as motivation to answer questions about meaning. Nine further themes were identified, such as "everything happens for a reason", "a challenge" and "personal growth" which McGrath (2004) conceptualised as the "spiritual journey". McGrath (2004) added that there were times when the individuals were not on the "spiritual journey" such as when they felt cynical, were in pain, or felt like they had

no choice. McGrath termed this as "spiritual pain". However it is not clear from the study if the participants refer to their experience as a "spiritual journey", or their low points as "spiritual pain", or if McGrath (2004) has devised these terms.

McGrath (2004) noted the contradictions in participants who were not religious but were using religious language, for example discussing being "protected" and a "higher being". Furthermore, a key spiritual notion was identified as "everything happens for a reason", leading to thoughts of being "chosen" for the illness and "saved" for a reason. Thus surviving the illness was a sign of being protected and everything working out favourably in the end, again using language which suggests the presence of a higher being or deity. The findings showed a strong commonality in statements, which McGrath concluded as an indication of a shared spiritual framework.

The majority of participants in McGrath's (2004) study remarked that they were glad they had embarked on a spiritual journey; although they were not sure it was necessary to become ill to go through the same process. Many saw their fresh experiences of meaning as the start of a new phase in life, and a motivation to start taking responsibility in their lives. Also, the fact that they were able to embark on a spiritual journey was deemed an achievement and a reason to be proud. McGrath (2004) noted that their illness allowed them a different "lens" with which to evaluate a negative experience as having positive outcomes. However interestingly, many individuals reported that they postponed meaning-making until well after their treatment had been completed. Thus they felt reflection was only possible once the "battles" were over. During times of pain or physical distress, participants reflected that they were unable to look at the bigger picture, and their focus was purely on survival.   The participants claimed that to put existential plans into action the physical body must be willing. Consequently it is possible that asking the same questions of people in the terminal stages of their illness is likely to yield different answers since they would be unable to postpone meaning making to when they are not experiencing any symptoms. Furthermore since many of the comments about spirituality in this study make reference to the meaning of survival suggesting that individuals may have different concepts of meaning when they are aware that they will definitely not survive their illness.

1.5.4 Watts (2009) Meanings of spirituality at the cancer drop in.

Watts (2009) used an ethnographic method at a British 'cancer drop-in' to explore the meaning of spirituality in the lives of people suffering from cancer or those who have been bereaved by cancer. Participants were observed at the centre over fifteen months, some of which were actively ill, some were in remission and others who had been bereaved from cancer. It was found that the key component of spirituality was connecting with family and friends as well as wider social networks. During the time of observation the researcher found that formal religion was not a major part of the individuals' lives as only two participants made any reference to religious faith.

Connections to families, friends and others were regular themes throughout their interactions at the drop-in. Watts' (2009) noted that this was especially important for the individuals who were ill. For some of the people at the drop-in 'neighbourliness' was important, and gave them the opportunity to reciprocate helping others who were also facing difficulties. A number of the individuals were active in their local community despite their own health problems and participants commented that their volunteer work kept them going, and prevented them from not knowing what to do with themselves. Watts (2009) considered that having a role that was not related to their cancer gave the individuals a sense of purpose, and that citizenship was a primary factor in spirituality. This lead Watts (2009) to the interpretation that individual's involvement in the community helped confirm their self worth and sense of achievement. Thus Watts (2009) concluded that *"an essential attribute of 'being' for this group was 'doing' and mainly 'doing' for others"* (Watts, 2009; p. 90). However some participants were fearful about how to continue their roles as their health deteriorated.

Watts (2009) concluded that an important component of spirituality is maintenance of the congruent 'self'. Spirituality was therefore about seeing themselves as independent, worthwhile human beings preventing the dissolution of personhood that can occur through serious illness. The main theme identified was the importance of interpersonal relationships, which allowed them to reflect themselves and their achievements.

This study was a useful method of exploring spirituality creatively without imposing terminology or definitions on the participants. However there remains the question as to whether these findings are actually referring to "spirituality". Watts (2009) noted that none of the participants explicitly referred to "spirituality", but she concluded that because these factors were so intertwined with their everyday being and definition of personhood they were spiritually significant. Therefore it would be useful to further explore if these findings resonate consciously with people in an interview about spirituality. Furthermore the participants included carers of people with cancer as well as individuals who were ill. Therefore it would be interesting to consider if the experience of spirituality was the same for both sets of individuals given their different life situations.

1.5.5 Thomas and Retsas (1999): Transacting Self Preservation: A grounded theory of the spiritual dimensions of people with terminal cancer

Thomas and Retsas (1999) looked at spirituality and meaning-making in people with terminal illnesses. The research questions were what are the spiritual experiences of people with terminal cancer? How do people with terminal cancer create meaning and purpose in their living and dying process? And how can this meaning be understood from a spiritual perspective? However participants from Australia with varying spiritual and religious beliefs were not directly asked these questions and instead instructed to describe their feelings since they were diagnosed with incurable cancer. Based on experience, Thomas and Retsas (1999) thought that spiritual issues would become more prominent as individuals approached death and used these beliefs to make sense of life. Using grounded theory to analyse their data, Thomas and Retsas (1999) found one single unifying theme to describe the phenomenon called "transacting self-preservation", which refers to the process of developing spiritual awareness as individuals make sense of and come to terms with their diagnosis. The phases identified describe coping strategies the individuals used to discover a meaningful existence when facing death; *"Transacting self preservation implies deeper levels of understanding self through spiritual growth, spiritual perspective, spiritual awareness and spiritual experiences"* (Thomas and Retsas, 1999; p. 192).

According to Thomas and Retsas (1999) evolution of this process is dependent on three dynamic and interconnected behaviours. The first stage of "taking it all in" begins when an individual receives a diagnosis of cancer. Responses include shock, fear, unpreparedness, denial and unacceptance. Some participants evaluated their past behaviour and concluded that if they had not lead a good life then cancer could be perceived as deserved, or a punishment from God. In the second stage of "getting on with things", the initial shock of the diagnosis had worn off and individuals were mobilising themselves into action by connecting themselves with the self, others and God or another Higher Being. Participants described reaching out to a wide range of networks, including family, friends and other support systems, which generated feelings of love and hope. Friends who had remained supportive were identified as important sources of support, particularly in reducing depressed and hopeless feelings. Having a connection with other people who have cancer was also helpful, as participants often found themselves in a world of only discussing cancer. Individuals reported that these relationships helped them feel understood and less alone. This stage also involved making meaningful relationships with healthcare professionals during their caring activities. A few participants recognised religion as a way of "connecting" which involved activities such as prayer meditation, listening and talking with reference to God, angels and Higher Beings.

The final stage of "putting it all together" consisted of creating meaning in their terminal cancer experience and discovering self. This was described as the first time that people looked at their lives as a whole. The final stage was often expressed as a shunning of materialism, and sense of being grateful for their life and being better off than others with physical suffering. Participants reported wanting more from life and doing everything now rather than putting it off which often lead to a sense of empowerment and confidence. Themes of forgiveness, transcendence and expanding consciousness emerged at this stage. Some individuals regarded this stage as "becoming spiritual". Thomas and Retsas (1999) concluded that participants facing a premature death (defined as under the age of 70) held different meanings of death from participants over the age of 70. The priorities of the younger individuals remained with 'unfinished business' such as children growing up and achieving in their professional life. However all participants were united in their faith in doctors,

self, treatments and/or God which gave them coping resources and provided them with a source of strength.

Although Thomas and Retsas (1999) found that some participants in the third stage of "putting it all together" regarded this stage as "spiritual", they conceptualised spirituality as the whole journey without any justification. Furthermore, the results seem to refer more to the individual coping strategies rather than giving an in-depth insight into the experience of spirituality and meaning-making. Thus the results reflect more about what the participants *did* in a practical sense, which lacks an exploration of the emotional experience of the participants.

1.5.6 Chao, Chen and Yen (2002): The essence of spirituality of terminally ill patients.

Chao et al. (2002) interviewed six people in Taiwan who were terminally ill about their experience of spirituality. "Spirituality" is a vague and abstract term in Chinese culture and therefore the authors attempted to gain rich descriptions of spirituality (Chao et al., 2002). Participants were aged between 20-83 years old, and included four Buddhists, one Protestant and one Catholic. Using an unstructured interview, participants were asked to describe their thoughts, feelings, beliefs and experiences related to the essence of spirituality. Answers were analysed using hermeneutic phenomenology and four constitutive patterns were found: communion with self, communion with others, communion with nature and communion with a higher being.

Communion with the self was described as discovering the authentic self. Participants expressed embracing wholeness, however contradictory, through a process of life review. Inner peace was identified as important in negotiating inner conflicts and achieving self acceptance. Communion with others was recognised as having a caring relationship with others, but without over-attachment. For example one woman described being able to let her children go and giving them their own destiny. Reconciliation was also important in communion with others; spirituality was associated with being forgiven and to forgive others. Communion with nature involved marvelling at the beauty of the world, an experience which could be

achieved through complementary therapies such as music and aromatherapy. Finally communion with a higher being included faith, hope and gratitude.

Although hermeneutic methodology in this paper has allowed spirituality to be explored freely, all participants were religious which again leads us to question if the themes are relating to spiritual or religious beliefs. There is no discussion as to whether the participants referred to all themes as spirituality.

1.5.7 Summary

From reviewing the literature it seems that the qualitative studies exploring spirituality and meaning-making lead to similar methodological challenges as cited in the quantitative literature. Firstly, as with the quantitative literature, some of the studies interviewed mainly religious participants leading to doubts about whether their findings of "spirituality" are in fact referring to religious beliefs. Also Thomas and Retsas's (1999) focus on coping mechanisms, which also echoes the quantitative studies, leads to a rather flat conclusion about what spirituality and meaning-making means to the individual and instead describes how participants carry on with life in a practical sense. Finally, a major issue with all the studies described was the decision about what themes come under the heading "spirituality". There seems to exist a tension between asking broad questions in order not to impose limits on the descriptions of spirituality, and the struggle to bring the broad findings back into the label of "spirituality". Furthermore, since the majority of papers lack transparency about the decision process of defining spirituality, it is difficult to ascertain whether the label of "spirituality" is a considered process or an assumption on behalf of the researcher.

1.6 Lead into the Current Study

From looking at the theories and research relating to spirituality and meaning-making at the end of life, it seems that this is a difficult area to research fraught with methodological issues. At this point a dilemma is faced: should I conclude that there is a problem with the term "spirituality" and abandon researching this concept or

should I persevere despite the difficulties with the term? Drawing on my own personal experience of working with individuals at the end of life, I believe that there is an important phenomenon arising in these circumstances that help the person to find meaning in their life. Although it is hard to study something that is not yet defined, I believe it would be unjustified to ignore this phenomenon on the grounds because we cannot pinpoint exactly what spirituality involves.

The purpose of the current study is therefore to explore the experience of spirituality and meaning making for people in the advanced stages of cancer from the perspective of the individual. The results are intended to inform all healthcare professionals working in this field since spiritual needs in patients with terminal illnesses are largely ignored, and will often fall to the responsibility of the hospital chaplain (Walter, 1997). The vast majority of research in spirituality has been reported in nursing literature. However, the findings of this study are anticipated to be of particular relevance to counselling psychologists working in the field of palliative care, since they are in a pivotal position to explore spirituality and meaning-making with individuals at the end of life (Carr, 1995).

2. METHODOLOGY

2.1 Background

The inspiration to write my thesis on end-of-life issues began during my first year of training when sadly a friend of mine died suddenly from cancer. The news of her death shocked me to my core because it had never occurred to me during her illness that her dying was a real possibility. The fact that I was so surprised that this could happen added to my disbelief – surely I knew all people will die at some point, and unfortunately some sooner than others? Looking around me at peoples faces when I told them this news, I began reflecting on the attitudes towards death and dying in our culture. It was obviously a topic that people found deeply uncomfortable discussing, and people were quick to establish differences between themselves and my friend as if to say "it won't happen to me" before closing down the subject. As a Trainee Counselling Psychologist I thought I was more accepting of the "truths" in life but my reaction made me question just how comfortable am I with the concept of death.

Deciding to explore this further, I took a part-time job at the Marie Curie Palliative Care Research Unit to assist with a study investigating the effect of spirituality on physical and emotional distress in people with advanced cancer. I found going to people's houses and discussing these topics with them absolutely fascinating and I often left their house feeling uplifted and felt I had learnt so much about what is important in life. I found myself wondering how did they find the strength to talk so calmly about what was happening to them? Would I be able to do that? What keeps them going in life knowing that they do not have much time left? However, the study involved administering a battery of questionnaires, and spirituality was measured using the Beliefs and Values Scale (King, Jones, Low, et al. 2006). Asking people set questions where they had to answer "strongly agree, agree, neutral etc" seemed so limiting, and often people said they were unsure how to interpret the terminology used within the questions. One day a particularly vivacious lady put the questionnaire down and said "It's all bollocks. How can I possibly answer if I am spiritual in one word?".

So in response to the lady who thankfully was so honest, I decided to explore the concept of spirituality in people with advanced cancer from a qualitative perspective, allowing individuals to describe their experience within their frame of reference and without the limitations of a set number of predetermined questions. Given that society seems so scared of discussing death and dying, I felt it was really important to give people a voice at the end of life so that as health professionals, families or friends we had a better understanding of the type of experience people may be going through at this stage of life. I wanted to know how did people make sense of life when they were dying? Did they start thinking about the bigger picture when they found out their time was limited? I felt spirituality was a concept that encompassed these sorts of issues, although I was also keen to discover if this was even the right word for describing the phenomenon.

2.2 Research Questions and Research Aims

Given that spirituality is such a difficult concept to define, I wanted to start with an open, orientating question and see how the study evolved. The research question was therefore "what is the experience of "spirituality" and meaning-making at the end of life?". The word "spirituality" was left undefined to allow people to explore their own definitions during the research. I had anticipated that the study would be unfolding and more specific research questions would be posed as the study progressed.

2.3 Conceptual Framework

The focus of this study was to explore individual experience of "spirituality" rather than search for a universal truth of "spirituality". To pursue a concise definition of "spirituality" that covers all individual beliefs and values would most likely lead to an overly vague concept that is no longer meaningful to the individual. Therefore a

qualitative framework was adopted since this allows an exploration of the personal meanings which a situation has for an individual (Ashworth, 2003).

As discussed in the introduction, existential philosophy provides an appropriate framework to discuss "spirituality" at the end of life. Existentialism is a philosophy derived from phenomenological research methods. Phenomenology was originally pioneered by Husserl (1931; 1967) at the turn of the century as a method of analysing objects of study (physical processes, geographical features or psychological phenomena) as they appear to us in our consciousness (Langdridge, 2007). Husserl (1931; 1967) argued that intentionality is an essential component of consciousness. This refers to the idea that to be conscious, we are always conscious of *something* (Langdridge, 2007). His approach overcame the Cartesian duality between the mind and the world since we cannot be separated from the world; consciousness is always reaching out to something (van Deurzen and Kenward, 2005). Thus the focus of Husserl's (1982) phenomenology was related to the way things appear in our consciousness. The purpose of this type of study is about the relationship between people and their world (intersubjectivity) and not about the thought processes within the brain (Langdridge, 2007).

Husserl (1931; 1967) argued that the 'lifeworld' can be understood as the individual's pre-reflexive experience without interpretation. Therefore phenomenology is the study of the lifeworld as we immediately experience rather than as we conceptualise, categorize, or reflect on it (Husserl, 1931; 1967). A key epistemological strategy for Husserl (1931; 1967) was "phenomenological reduction" which involves bracketing off judgements and pre-existing knowledge to view the world with fresh eyes. Husserl (1931; 1967) believed you could take a "God's eye view" of experience and free yourself from all biases in understanding. However, the notion of whether or not we can completely bracket off our preconceptions created a division between phenomenologists. Transcendental phenomenologists, such as Husserl (1931; 1967) argue that it is indeed possible to experience a phenomenon without any preconceptions as if looking thought the eyes of another person (Langdridge, 2007). However existential phenomenologists, such as Heidegger (1927; 1962) challenged Husserl's (1931; 1967) "God's eye view" approach to phenomenology, and instead proposed a more existential view, maintaining that a person cannot ever be truly

separated from their world and presuppositions. Heidegger (1927; 1962) referred to humans as *Dasein*, which translates as "being-in-the-world", to reflect that our experience can not be separated from the world. Heidegger claimed that we experience a thing as a "something", and therefore it is already interpreted; nothing can be encountered without reference to the person's background understanding. To explore an object of study therefore requires being as aware as possible of our biases and accounting for these interpretive influences.

Gadamer (1975), building on Heidegger's theory in *Truth and Method*, suggested that conversation is the heart of all understanding and it is through a shared understanding that things reveal themselves. In line with Heidegger, Gadamer (1975) claimed that our understanding is limited by our horizons, which refers to the fact that our position dependent is on our history and culture. However, our horizons are constantly changing and it is through the fusion of multiple horizons that we can gain a mutual understanding of worldviews. To interpret another person's communication relies on an understanding of both the parts and the whole of the communication since knowledge is dependent upon both the understanding of language and the totality of language at that time (including the author's embeddedness in history, culture and so on). To illustrate this concept, Schmidt (2006) provides the example of a sentence: *"one cannot understand the whole sentence until one has understood the parts, but one cannot understand the parts, a word's specific meaning, until one has understood the whole sentence"* (Schmidt, 2006; p. 14). This interpretive process is described as the "hermeneutic circle" which requires interpretation to move from the parts of experience to the whole of experience and back and forth again to increase the depth of engagement with the understanding of the texts (Polkinghorne, 1983). Kvale (1996) viewed the end analysis as occurring when one has reached a place of sensible meaning, free of inner contradictions, for the moment.

Given that existentialism and phenomenology are so closely linked, I considered phenomenology to be the most appropriate framework to guide the research. The Heideggerian (1927; 1962) focus on how we are (rather than Husserl's (1931; 1967) emphasis on how we understand) was consistent with the concept of individuals striving towards meaning-making in the world, which was the central object of exploration in the study. Therefore my approach was interpretive rather than

descriptive. However, there are as many styles of phenomenology as there are phenomenologists (Spiegelberg, 1982), and so deciding on an interpretive methodology required careful consideration of the different approaches.

Initially I considered Interpretative Phenomenological Analysis (Smith, 1996), since it is a well established strand of interpretive phenomenology. However, it has been argued that the emphasis on individual cognition within this approach suggests a Cartesian conceptualisation of the individual due to the emphasis on the individual having a set of cognitions which he/she uses to interpret the world (e.g. Willig, 2008). This did not fit my desire to follow Heidegger's existential view of consciousness and the world being inseparable. Subsequently, I decided on van Manen's (1990) Hermeneutic Phenomenology, which is a coalescence of Heidegger and Gadamer's philosophy (Robertson-Malt, 1999). van Manen (1990) stated that phenomenology begins with the lifeworld, and is the search for what it is to be human. He argued that prejudices do not get in the way of understanding phenomena, but instead make the research meaningful. Furthermore, the process of phenomenology allows us to test our understandings and expand our horizons.

van Manen (1990) emphasised that there is no method explaining how to do hermeneutic phenomenology. Instead he claimed that a method will emerge uniquely in the context of the phenomena being investigated (Langdridge. 2007). Polkinghorne (1983) suggested the term "methodology" was more appropriate than method, referring to the creative approach in understanding. van Manen (1997) stated that methodology requires the researcher to be reflective, insightful, sensitive to language and constantly open to experience. Nevertheless, van Manen (1990) did propose six guiding principles to carrying out hermeneutic research:

1. Turning to a phenomenon which seriously interest us and commits us to the world.
2. Investigating experience as we live it rather than as we conceptualise it.
3. Reflecting on the essential themes which characterises the phenomenon.
4. Describing the phenomenon through the art of writing and rewriting

5. Maintaining a strong and orientated pedagogical[1] relation to the phenomenon

6. Balancing the research context by considering parts and the whole.

Hermeneutic research is fundamentally a writing activity, and closely follows Gadamer's (1975) theory that conversation is the heart of all understanding. van Manen (1990) claimed the focus of phenomenology should always be on creative engagement with language, which can be used to reveal something that was previously concealed. I was keen to find an approach that was flexible enough to cope with the broadness of a concept such as spirituality and therefore considered hermeneutic phenomenology to be appropriate given that the language used to describe this abstract phenomenon is likely to be varied and metaphorical. Furthermore, van Manen (1990) argued that texts should speak to the reader not only cognitively but also emotionally. Given that interviewing people in the final stages of life is likely to be highly emotive, I felt strongly about preserving the emotional content of the interviews in the analysis, which can be achieved using this methodology.

2.4 Ontological Position

By using hermeneutic phenomenology, the research aimed to discover how participants viewed the world via the medium of language (Annells, 1996). Thus the purpose was to gain a deeper understanding of the phenomena of spirituality at the end of life, rather than to seek empirical facts or construct theories about individual experience. Since the knowledge gained is subjective rather than objective, it was assumed that there would be many different perspectives of the phenomena. Bergum (1991) claimed that the findings from hermeneutic phenomenology can be compared to a prism: as we turn the prism, it catches the light and the prism changes; one part becomes hidden as another opens. Furthermore, there was no end point, as questioning continues beyond the research with the readers of the text who will bring new perspectives to established interpretations (van Manen, 1990).

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[1] Landridge (2007) suggested substituting the word psychology for pedagogy to make the principle more appropriate for researchers in psychology.

Philosophical hermeneutics is argued to be more concerned with the ontological perspective than epistemology since the phenomenology reveals "a way of being" rather than understanding as a way of knowing (Reeder, 1988). Consequently the epistemological stance is not a dominant feature of the philosophy (Annells, 1996). However, some authors have debated over using epistemological terms such as constructivist (Guba and Lincoln, 1985), interpretive or constructivist-interpretive (Denzin and Lincoln, 1994) to describe hermeneutic phenomenology. For this study, I considered the epistemological stance unhelpful since the aim was not to find out *how* we know what we know but instead to study the nature of being from an ontological standpoint. According to existential phenomenology, *ontological* conditions are the givens of human existence. However, when these ontological conditions are considered by a particular human being are said to be *ontic,* since the givens have been expressed uniquely by that person dependent on their context (Spinelli, 2007). The research is therefore defined as "hermeneutic" meaning that it aims to understand the life experience of the participants by searching for both universal meaning (ontology) and meaning from that specific person (ontic). Thus the data is understood through the hermeneutic circle by examining the interdependent influence of both the parts and the whole, acknowledging both the givens of existence and the expression of those givens by the individual.

Taking a hermeneutic approach assumes that individual reality is specifically constructed depending on the context of the person (Lincoln and Guba, 1985). It respects the capacity for self knowing and encourages the inquirer to reflect on this knowledge by identifying the various contexts that influence the person's behaviour (Robertson-Malt, 1999). By taking a hermeneutic approach, it is presumed that meaning is revealed by language and that human experience has a semantic and textual structure (Packer and Addison, 1985). Furthermore, the researcher is implicated in the findings given that all interpretations rely on the reflexive attitude of the researcher (Willig, 2008).

2.5.1 Sample

Eight participants were recruited from Eden Hall, the Marie Curie Hospice in Belsize Park. Individuals attending Eden Hall experience chronic health issues and many have a diagnosis of cancer. The hospice has a number of inpatient wards, for symptom control or respite, in addition to outpatient clinics and day therapy units. This was considered a good location for the study since I knew many of the staff through my previous job and was also aware that the Director of Medicine had a particular interest in exploring spiritual needs of his patients. Also from previous experience I was aware that the individuals attending the hospice had enormous respect for the staff and service, and therefore thought it is likely to be a place where people felt comfortable talking about their experience.

The inclusion criteria consisted of: being over the age of 18 years old, able to speak fluent English (since data was collected in the form of a verbal interview), identifying themselves as wanting to talk about their experience of "spirituality" and meaning-making, and in the advanced stages of cancer. "Advanced cancer" was defined as having a life expectancy of less than one year. This was a somewhat arbitrary figure but was considered appropriate given that the phenomenon to be explored was the experience of "spirituality" at the end of life. It was reasoned that a person with a life expectancy of over a year may not consider themselves to be in the 'final stage of life', and could therefore be referring to a different experience. A further consideration was the physical health of the potential participants. Often studies in palliative care will only approach patients with a Karnofsky score (Karnofsky and Burchenal, 1949) of above 80, which refers to their physical status. However, avoiding people who need help with physical needs could lead to missing important contributions from people who may provide valuable input. Therefore people who identified themselves as having experience of "spirituality" and meaning-making and who were willing and able to take part in an interview were included. There were no restrictions regarding their status as inpatients or outpatients.

Individuals were not considered if their death was imminent (e.g. within the next few weeks) because participants would be asked to be interviewed a second time, and also because the interview may have been traumatic if they were very ill. Also individuals who were considered to be emotionally distressed were excluded since this would not have been ethically appropriate. Judgements about the individual's life expectancy and emotional well-being were made by the staff at the hospice, a measure which was considered ethically appropriate.

Phenomenology tends to use small samples in order to illuminate the richness of experience (Baker, 1992). After eight participants were interviewed data collection was stopped since it was decided that there was a wealth of rich data to progress onto analysis. The eight participants consisted of three males and five females with ages ranging from 44 to 80 years old (*see box 1. "introducing the participants", p.72*) Researchers using a phenomenological approach tend to seek out a fairly homogeneous sample in order to ensure that only one phenomenon, rather than several phenomena, emerge from the analysis. However the degree of homogeneity depends on the topic investigated, the interests of the researcher and the constraints of the study (Langdridge, 2007). In the current study participants were homogenous in that they identified themselves as having experienced "spirituality" and all had a life expectancy of less than a year. However it was not possible to match participants in terms of socio-demographic variables since the hospice population was diverse. Thus the participants were from variety of backgrounds, which was considered in the analysis and will be explored in more detail in the discussion.

Since the concept of "spirituality" was left undefined in the research question, there was a risk that participants would not consider themselves appropriate for the study depending on their definition of "spirituality". For example Herman (2001) found participants initially defined spirituality as a belief in God, although later in the interview it became clear that their notion of spirituality referred to many other parts of their existence. To avoid excluding potential participants, it was explained to the individuals identified by the palliative care team that "spirituality" did not necessarily have to imply religion, rather that the term "spirituality" was only a suggested label and participants could use any terminology that they felt appropriate.

2.5.2 Data collection – instruments

It was decided that an unstructured interview would be the best method of data collection since this type of interviewing can potentially reveal the richest data. This is also a popular method when using hermeneutic phenomenology since it helps the researcher to take a fresh look at the phenomenon without imposing any preconceived ideas (van Manen, 1990). Given that "spirituality" is such a broad topic, I felt it was important to let the participants describe their experience in their own terms without imposing my own pre-existing judgements about what "spirituality" might be like at the end of life. Although it is also possible to use other mediums for hermeneutic phenomenology, such as diaries, art work and observation (van Manen, 1990), it was considered that an interview would be the most achievable and least taxing form of research for participants who are physically unwell. Also the pace and timing of this kind of interview was flexible and could be adjusted to the individual, which was particularly important given that participants may have had limited concentration spans as a result of pain or fatigue.

As advised by Moustakas (1994), the interview was informal and interactive using open-ended comments and questions. van Manen (1990) compared the unstructured interview to be like "talking between friends". At the beginning of the interview I aimed to create a relaxed trusting atmosphere by starting with a social conversation as suggested by Seymour (1998). I then explained to participants that I wanted to understand their experience of "spirituality", or whatever term they preferred to use, and how they made sense of life. I advised them that I did not have a specific question schedule and asked for them to explain their experience using their own words. Thus the participant was invited to be a co-researcher in understanding the phenomenon (Holloway, 1997). Following the guidelines of Laverty (2003) the first question, "what is life like for you at the moment?", was broad and open-ended. I then asked clarifying and probing questions using the participant's language to facilitate rich descriptions of the phenomenon. Examples of these questions include: How did the experience affect you? What changes do you associate with the experience? How did the experience affect significant others in your life? What feelings were generated by the experience? Have you shared all that is significant with reference to the experience? (Kvale, 1996). I maintained the research question in

mind in order to ensure the interviewee was consistently orientated to the subject. I also had an aid memoir with different prompting questions and terminology in case the individual was getting stuck in discussing spirituality. The questions included:

- Has anything changed in the way you think/feel about life?
- Have your beliefs or values changed?
- What is it like to live with your illness?
- Have you changed the way you think about yourself? Others?
   Your body?
- What is your meaning/ philosophy in life?
- How do you feel about yourself/the world/ the future?

This list of questions was decided on from key concepts in the literature and discussions with the staff at the hospice about different words the participants use in their conversations. However the questions only served as suggestions and I found that I rarely needed to refer to these notes during the interview as many of the participants were able to talk at length without much prompting. McGrath (2004) similarly found that an aide memoir was not necessary and participants spoke more freely when the interview guide was not used. The main terminology I had to revise was in reference to the person's illness rather than words used to describe "spirituality". The first participant I interviewed appeared a little upset about my use of the word "diagnosis", and so I was careful to use the words that the individuals chose to describe their health. The interview finished when the person lapsed into silence, signalling that they had said all they could say about their experience at that time.

2.5.3 Data collection - procedures

Originally it was decided with the staff at the hospice that potential participants fitting the inclusion criteria would be identified at the Multidisciplinary Team meeting. Once they had been identified the staff were going to ask participants to sign an initial consent form (*see appendix i*) to allow their name and contact telephone number to be passed on to the researcher. I would then ring the individual to explain the study in more detail and establish if they were interested in taking part. However, because the

staff were so busy only one participant was recruited in this manner. Instead it was decided with the nurses at Eden Hall that it would be easier for me to come to the Day Therapy Unit one day a week and meet potential participants with them while they were attending the hospice, thus saving the nurses time. Therefore initial consent forms were not required for seven of the eight participants since they gave me their contact details directly. This method was very successful, and only two individuals decided not to take part in the study, citing poor health as the main reason. After asking individuals if they would like to take part, we arranged a convenient time and place for the interview. I gave them a leaflet explaining the study to remind them of what we had discussed (*see appendix ii*). The leaflet included my contact details if they had any questions.

Initially the title of the study on the patient information was *A study looking at spirituality and meaning-making in advanced cancer*. However it was decided in a meeting with the staff at the hospice that this title was not suitable for potential participants since they may assume that the term "spirituality" was in reference to religion. They also considered the phrase "meaning-making" to be confusing and only relevant for researchers. Consequently the documentation was changed via a substantial amendment with the ethics committee (*see appendix iii*) and the title became *Searching for meaning and making sense of life when living with advanced cancer*. The term "spirituality" was then nested within the context of the participants information leaflet and explained verbally to interested participants.

The interviews took place in a location chosen by the participant to be the most relaxed or convenient. For three participants this was their home, four people were seen in a counselling room at the hospice, and one person was interviewed while they were staying on the ward having their medications reviewed. Before the interview started I explained what the research was about, asked them to read the participant information sheet (*see appendix iv*) and gave them an opportunity to answer questions. I explained that the research would be written up as my thesis for my Doctorate in Counselling Psychology and that data would be confidential and transcripts would be made anonymous. If they were still willing to take part, which they all were, they signed a consent form to confirm that they agreed to take part in the study, but understood that they were free to withdraw at any time and this would not affect their

care (*see appendix v*). I then started the interview, which was recorded using a digital Dictaphone. The length of the interview was dictated by the individual, and the time varied between 30 minutes to 1 hour 15 minutes. I was wary that the individual could get tired and encouraged participants to say if they felt there were not able to continue.

After the interview ended the participant was debriefed, since often individuals will have shared a lot of personal and emotional experiences and will be left wondering what will happen to their contributions (Kvale, 1996). This was therefore an opportunity to ask any further questions or share any concerns. Although this was not an issue, it was planned that if anything concerning had been discussed during the interview then the individual would be asked if I could share this information with the palliative care team.

The initial research proposal had planned to interview participants for a second time to allow individuals to add, clarify or change any information they had given in the first interview. This was regarded as important since it may have been the first time that participants had spoken about this subject in depth, and therefore they may have developed further thoughts since the initial interview. I planned to summarise the first interview using the participant's language, and feed this back to the individual to check if this was everything they intended to say (*see appendix vi for an example*). However, in the first five interviews, only two people agreed to meet for the second interview. Of the other three, two stated that it was not necessary for them to add or change anything and one was feeling too unwell to meet again. In response to this feedback the next three participants were told that this was an optional step rather than necessary for the research. A further two participants wanted to meet again, and one felt it was not necessary. Only one out of the four participants interviewed a second time wanted to add more information. Our first interview finished when she had to attend an appointment at the hospice and so she continued where she had left from the first interview. This was analysed as one continuous transcript since it was a continuation of the first interview. The rest of the participants attending a second interview commented that they felt the summary had captured everything they wanted to say and did not have anything further to add.

2.5.4 Reflexive diary

Given that understanding in hermeneutic phenomenology is a product of reflection of interpretations and experience, a reflexive diary was kept throughout the research to record thoughts and feelings during the study. Immediately after interviews, emotional responses and non-verbal expressions were recorded for each participant. Also thoughts about the phenomena were recorded during analysis and whenever I was inspired by a text or a conversation, since interpretations are constantly being made before, during and after data is collected (van Manen, 1990).

A fundamental concept in phenomenology is intersubjectivity; the idea that we are inextricably involved with others and the world (van Deurzen and Kenward, 2005). Therefore by keeping a reflexive diary I was able to examine how I influenced the research process since I was in a relationship with my participants and the research process. I was able to reflect on my perceptions and understanding in order to challenge my assumptions and understand the fusion of horizons between the subject and object (Gadamer, 1975). In doing so I ensured that the researcher was not separated from the research process and the decision trail was made transparent (Koch, 1996).

2.6 Ethics

The ethics of the study were considered in accordance with the British Psychological Society Ethical Guidelines, and NHS and R&D ethical approval was gained prior to data collection (*see appendix vii*). All participants were informed of the true nature of the study, and therefore, before gaining consent, all individuals were briefed on what would be expected of them as well as the purpose of the research. Participants were informed that they were free to withdraw from the study at any time and that this will not affect their care. All data was stored confidentially since consent forms were separated from data, and all identifying variables, such as names and addresses were removed from transcripts. Audio-recordings were immediately downloaded onto a computer, and the file was removed from the Dictaphone. Data was stored on a computer protected by a password to ensure confidentiality and participants were

advised that the research would be written up as a thesis for a Doctorate in Counselling Psychology and that all quotes would be anonymous.

Although it was not anticipated that participants would be caused any harm during the research, it was acknowledged that potentially individuals could become distressed when talking about the subject matter. As a safeguard, the multidisciplinary team was instructed to refer only those whom they consider to be emotionally stable enough to talk about "spirituality" and meaning-making. However, had an individual become distressed, they would have had full access to the counselling service at Eden Hall. Also when designing the research it was thought that participants could potentially benefit from the process. Benzein (2001) reported that individuals claimed to feel better after the interview as a result of being able to formulate their thoughts and feelings.

Since the participants in the study were physically unwell, it was vital to consider their well-being during the interview. Individuals were advised before the interview started that if they were feeling unwell to tell the researcher immediately and stop the interview. Although this did not happen, a second interview would have been scheduled if the participant had been willing to continue the interview on another occasion. I was also wary of invading the individual's privacy and therefore encouraged the person to choose a place in which they felt comfortable to conduct the interview.

Another important consideration was to maintain my relationship as a researcher and not as a counselling psychologist. However, this was not easy given that the differences between research and therapy are not always clear (Hart and Crawford-Wright, 1999). Both therapy and phenomenological research aims to understand the participant, explore and clarify their world and empathise with their situation. Thus as a researcher I was at risk of establishing a relationship with the individual that allowed them to reveal too much and leave them empty after the interview had concluded. In response to these blurred boundaries, I endeavoured to only discuss topics that the participant was willing to share, and not push them into answering questions they were not comfortable divulging. However it was hard to break the relationship once the interviews were complete, and I had to reiterate my brief

involvement with a few individuals who thought I would be able to see them on a regular basis. This felt quite unnatural to me as a therapist given that my relationships with clients in a therapeutic setting are much longer and dictated by the clients' needs rather than the research needs.

2.7 Methodological Reflexivity

There are a number of considerations regarding how the method influenced the type of knowledge produced in this study. Firstly, the use of unstructured interviews was quite hard to put into practice. Some participants clearly found talking at length without any directive questions a natural process, whereas a few participants struggled and asked me to ask them questions. Therefore the richest data and most insight is likely to come from the more eloquent and talkative individuals (Finch and Mason, 1990), which is likely to lead to more emphasis on their experience in the analysis. Also, by listening to the accounts with an open mind and acknowledging my preconceptions, I found it challenging to decide whether the person was talking about something relevant to the phenomenon of "spirituality" or not. For example one woman discussed world politics which I initially thought may have been off the subject, although I later reflected that world issues were perhaps her for it was part of her experience of "spirituality". I discussed my concerns with my supervisor who reminded me to keep an open mind to what individuals were describing, since the experience of "spirituality" could differ between individuals. She also listened to some of the tapes so we could discuss the conversations and think of ways to improve future interviews, such as matching participants use of language.

Giving participants the choice of where to conduct the interview seemed to contribute to a more relaxed interaction. I found a lot of the participants were extremely busy, and therefore appreciated my flexibility. Also, for many the hospice was a time in their week that they could have frank conversations with others about how they were feeling, and I found being affiliated with the hospice automatically granted me a certain level of trust and honesty. However I felt that for one participant that I interviewed, the setting was not conducive with a relaxed atmosphere. He was in bed when I arrived at his house, and his carer got him up and into a dressing gown whilst I

was in the room which seemed to make him feel uncomfortable. This was the only instance where I felt like I had intruded, and I considered this when analysing his data since his answers appeared to be quite guarded.

It was anticipated that the interview method would evolve over time. Therefore changes in the way people were recruited and the use of the second interview were welcomed. On reflection, the inclusion of a second interview reveals my assumption that participants would not have discussed spiritual issues in depth before. On the contrary, the individuals reported having well established beliefs and many stated that it was not necessary to revisit their comments in the future since they would have nothing to change or add. Perhaps, therefore, I was imposing my own uncertainty about spiritual issues or assuming that people would be shocked about their diagnosis and not sure about the meaning in life. This was again considered in the evaluation, and I used my reflections to further test my preconceptions of the phenomena.

2.8 Personal Reflexivity

Before interviewing any participants I spent some time trying to identify and examine my presuppositions and pre-understandings of the phenomena as recommended by Finlay (2003). van Manen (1990) claimed that the problem researchers have is not knowing too little but knowing too much about the phenomena. Thus the idea is to hold our preconceived ideas at bay and even turn this knowledge against itself. I considered what experience I had of end-of-life issues. Losing a friend relatively recently was bound to influence my thoughts about death and dying. I had experienced her illness as quite frightening and sudden. After this I had taken my own fears of death to personal therapy. Consequently, I was feeling more at ease with the idea of death, although the thought of losing people still filled me with sadness. During the interview process, analysing the data and reviewing the literature I have had to face my own truths of existence. Reflecting on my feelings during the interviews and discussing my feelings in personal therapy allowed me to embrace the idea of death more fully once I realised that to a certain extent I had been trying to ignore it's reality. Although this has been at times a difficult process I now feel a renewed sense of life and endeavour to live in the present moment. I feel this has

been a gift from my research and consequently I am extremely grateful to the participants for allowing me into their lives.

In terms of spirituality, I am not a religious person, but would regard myself as "spiritual". My own definition of spiritual is concerned with how humans relate to each other rather than a belief in a transcendental being. I personally feel that a sense of spirituality comes from intimate and genuine relationships with another person, or group of people, and that life should be about respect and love for other human beings and the world. However even being able to put these perceptions down into words was a hard task since my beliefs are both verbal and emotional, and thus I feel the previous sentence does not do much justice to my thoughts on spirituality. Therefore the experience of considering how *I* feel about life was useful in thinking about how participants would find expressing their thoughts on spirituality, as I found this difficult myself.

Furthermore, if I try to imagine how my beliefs would change or evolve if I was diagnosed with a terminal illness, I would predict that I would try and spend the rest of my time doing what I felt was important. I imagine I would try and think about the bigger picture in life, and perhaps try and connect myself with the world through nature as well as through other people. Therefore I attempted to bear in mind during the interview that this would potentially be my reaction, but that others may respond in a different way. Although I attempted to enter the interviews with an open mind, I was quite surprised about the number of different topics, such as relationships, religion, politics, gardening and so on, which were discussed in the interviews. The fact that this surprised me leads to me to reflect further on my preconceptions regarding what I had been anticipating from the interviews. I realised that I had been expecting more specific conversations about what "spirituality" meant to the individual as a concept, and whether this had changed over the course of their illness. Instead the interviews were broader in their content and people were not always clear about the link between what they were saying and their experience of "spirituality". Consequently I spent time with my supervisor discussing my feelings on the content of the interviews to dissect and explore my pre-understandings and open my horizons.

Before interviewing participants I was also aware that I believed that people are often ignored at the end of life because of other people's fear of death. My own experience, both personally and professionally, has been that people who were very ill or had recently been bereaved would often find themselves isolated as those close to them would claim they "did not know what to say". I thought perhaps my study would be useful for people to express their thoughts that they were not able to tell their family or friends, and that as a result they may find the interview an unusual and perhaps even an empowering experience. However, again this was all an assumption based on my own frame of reference and I realised over the course of the research that all participants viewed the research as helping me, rather than me helping them.

During the process of interviewing I discovered more assumptions and biases from both myself and the participants which I had not thought about before collecting data. van Manen (1990) claims this is likely to happen as we continue to review our interpretations of experience. A number of people asked me what my spiritual beliefs were, which lead me to reflect that perhaps by doing this type of research individuals had assumed that I was religious. When people asked this question I answered honestly, although briefly, to say that I did not belong to a particular religion but that I was interested in spirituality. I felt it was important to be genuine and not deflect this question as I wanted the participants to know that my position was being interested in other people's views rather than coming from a particular religious perspective.

Finlay (2003) claimed a major part of reflexivity is attending to the evolving relationship between researcher and participants. I found as I interviewed more people and became more relaxed about conducting an unstructured interview, the conversations became more informal and richer in depth. As I became more immersed in understanding the participant's world, rather than thinking about whether or not I was doing the interview right, I found I was better able to empathise with what they were saying and connect with them on a very human level. Whilst I was conducting interviews I read an *Intimate Death* by Marie De Hennezel (1995) which inspired me to think more about how I engage physically with a client. De Hennezel (1997) described her own therapeutic experiences with people in a hospice and advocated the use of physical connections with clients such as sitting on their bed, holding hands or giving people a hug if they requested one. Working as a

psychologist makes you very aware of your boundaries and I have always been wary of any physical contact with clients unless they explicitly initiate it. However, as noted by De Hennezel (1995), people in the last stages of life often find a lot of comfort from physical touch. By becoming more relaxed in my attitude and allowing the participants to guide the interview in terms of conversation and physical connectedness I noticed a big difference. One of the participants held my hand for the entire interview, I received numerous hugs and participants requested that I help them back to day hospital by holding their arm. I was particularly touched when on the second interview one of the participants brought me her art book and allowed me to read her personal stories and experiences. As a consequence of being more open to physical connectedness I feel that I was able to gain and more trusting and open relationship with the participants and really felt that I had stepped inside their world for the short time that I knew them.

van Manen (1990) claimed that phenomenological projects often have a transformative effect on the researcher. He stated that this type of research is a form of deep learning, leading to the transformation of consciousness, heightened perceptiveness, increased thoughtfulness and tact. I felt like I evolved both personally and professionally during the interviews as I become more open to the idea of really connecting with someone and trying to understand their world, as well as opening my mind to variety of interpretations of the topic of spirituality. As I walked away from the interviews sometimes I felt sad that the person was nearing the end of their life but a lot of the time I felt pleased to have had fascinating conversations with such interesting participants.

2.9 Intersubjectivity

As well as reflecting on my preconceptions, it was important to consider how my relationship with the participants affected the information being disclosed in the interview. I entered the relationship as someone affiliated with the hospice which made the participants immediately trust me. Since the individuals were so grateful to the hospice for the care they received, they were willing to be interviewed in order to return the generosity. I realised as the research progressed that this perhaps lead some

participants to agree to taking part in the research as a favour to the hospice, rather than being interested in talking about "spirituality". Consequently when it came to the actual interview, some participants were not entirely sure what the research project was about.

Another key element in my relationship with the participants was my own good health in comparison to their deteriorating health. There were a number of occasions where I became aware of my own physical health status. One lady commented that people in the "well world" can not understand people in the "ill world". Also many participants commented that it was comforting to talk to other people with cancer since they understood their experience. As someone who does not have cancer, I wondered if the experiences they shared and language they used was different for those that are ill and those that are well. I considered if they held back from more distressing material to avoid upsetting me or they felt that certain issues should not be discussed because I would not understand. However, I was also aware that being young and in good health meant some participants took on a grand-parenting role in our conversations. I felt they were teaching me about what is important in life and helping me to gain meaning in the absence of a crisis.

As someone who has a personal interest in the topic of "spirituality" and no religious affiliation, I approached the interviews with curiosity and an open mind. By not imposing my beliefs and reflecting on the participants' unique personal experience, I felt that the participants trusted that I had no hidden agenda and felt comfortable in exploring their experience without judgement. I also felt that my skills as a Trainee Counselling Psychologist facilitated the rapport and strengthened the research relationship. However, some participants perhaps had different expectations from a researcher and thought I may be more directive in my questioning. For these participants it took longer to build up the rhythm of the unstructured interview and I took time to explain the reasoning behind my approach.

2.10.1 Transcribing and poetic condensation

The purpose of a phenomenological inquiry is to make us "see" something in a manner that enriches our understanding of experience, not just cognitively but also emotionally.   Thus van Manen (1997) claims the results should not just answer "what does the text speak about?" but also "how does the text speak?". I felt it was important to preserve the expressive content on the interviews especially since the topic is highly emotive. However evoking an emotional response from the reader can be challenging, and as Heidegger (1927; 1962) asserts, language becomes dead as soon as it is fixed. Ohlen (2003) proposed poetic condensation as a method that can engage the reader to a deeper level of meaning by conserving the expressive content of a person's narrative. Ohlen (2003) argued that poetry discloses the nature of existence because it is creative, metaphorical and novel.   Poetry invites the reader to engage and be touched by the text (Ohlen, 2003).

After transcribing the text the transcripts were formulated into lines of poetry using Gee's (1991) model of poetic condensation, as suggested by Ohlen (2003). According to Gee (1991), oral narratives can be organised into sequences of lines which can then be shaped into stanzas (Gee, 1991). The start of a new line is denoted by a change of pitch in the speaker's voice, a difference in intonation or a significant pause. Thus how the text is said is crucial when establishing the structure of the lines (Gee, 1991). Gee (1991) argued that line patterns fall into stanzas. A stanza is indicated by a group of lines about a particular topic: *each stanza represents a particular perspective, not in the sense of who is doing the seeing, but in terms of what is seen; it represents an image, what the "camera" is focused on, a "scene""* (Gee, 1991; p. 23-24).   According to Gee (1991), lines are surprisingly often organised into stanzas consisting of four lines which are periodically punctuated by single line expressions. These interruptions usually reflect aspects of central meaning to the narrative (Ohlen, 2003).

Thus I established the lines of the poems by making use of accentuation, pauses and rhythm in the narrator's speech.   I then organised these lines into stanzas by

considering the content of the lines. Establishing lines was straightforward the majority of the time, but sometimes a section needed listening to repeatedly in order to identify the pattern of speech. Creating the stanzas was also relatively clear-cut and I often found that there would be a single punctuating line that did not belong to a stanza, signifying a significant statement. Some participant's speech fell more naturally into four line stanzas whereas for other participants the number of lines per stanza varied. (S*ee appendix viii for example of poetic condensation*).

As recommended by Ohlen (2003), I rephrased questions I asked as if the participant had asked it themselves. For example asking "what is life like for you at the moment?" turned into "what is life like for me at the moment?", since this is the mode in which the participant would have been asking themselves the question internally. Probing questions, such as "can you tell me more" and so on, were excluded from the poems since this was not adding meaning to the poem. Gee (1991) recommends using the entire narrative when creating poetic condensation. However I followed Ohlen's (2003) example of only including statements that were relevant to the phenomenon. For example, I excluded a section from one participant's interview which went into detail about her partner's career which I did not regard as relevant to the experience of "spirituality" and meaning-making. I also removed any narrative that would make the participants identifiable.

Gee (1991) suggests that stanzas fall into related pairs, creating strophes, and strophes make up larger idea units which he called parts. However the poetic condensation was stopped after creating stanzas, since it was decided that creating strophes and parts would begin an analytic process that would be departing from analysing the data using the hermeneutic circle.

2.10.2 Listening to the parts and the whole: Creating themes

Hermeneutic phenomenology deliberately moves away from the mechanical application of coding to allow the researcher to engage in the "free acting of "seeing"" (van Manen, 1990; p.79). Analysis is conducted by the hermeneutic circle, creating a constant dialogue between the parts of the whole. According to van Manen (1990) the researcher must look for both universal meaning (i.e. the ontological meaning that

is general to the situation) as well as particular meaning (i.e. the ontic meaning that is specific to that person/situation).

van Manen (1990) suggests three approaches to analysing data during hermeneutic phenomenology. These include:

1. Wholistic reading. This involves attending to the text as a whole and finding phrases that capture the fundamental meaning of the text as a whole.
2. Selective reading. This requires reading the texts several times to find sentences or phrases seem particularly essential or revealing.
3. Detailed reading. This is achieved by reading every single sentence or sentence cluster and analysing what the sentence reveals abut the phenomenon.

The process of moving between the parts and the whole had already begun during the poetic condensation when thinking about the division of lines, how they grouped into stanzas and the significance of single punctuating lines. After the transcript was made into poems I continued analysis by reading the poem as a whole and writing a summarising paragraph on what I felt the text communicated as the person's experience of "spirituality" and meaning-making. I then moved onto detailed reading, asking myself what this sentence revealed about the phenomenon and how this related to the whole poem *(see appendix ix for an example of detailed analysis)*. This was done by listening to the tape, as well as reading the transcript, moving through the text slowly and paying attention to all aspects of the communication, including silences (van Manen, 1990). Reflexive observations noted during data collection were used to enrich the analysis and to keep a record of a dialogue between the parts and the whole. I also reflected on how *I* felt as I was analysing the data to gain a deeper understanding into the phenomena. As Finlay (2003) recommended, I asked myself "how do I feel?", "What is the source of these emotions?"

After the detailed reading was completed I began selective reading. This involved rereading my notes from the detailed reading and looking at the whole transcript whilst thinking about how the data was organised in parts and how this related to the whole. Once I had thought about the different sections of the text, I re-read the poems

and considered which phrases particularly captured a concept. After the selective reading, I then rewrote a summarising paragraph which I thought captured the essence of the participant's experience of "spirituality" and meaning-making. Finally I drew diagram in summary since I found myself often thinking about participants experience pictorially. The diagram was viewed as a kind of "experiential map" which helped capture the experience as a whole *(see appendix x for an example diagram)*. As I worked through all the participant's transcripts, the previous analyses were used to help enhance the analytic process, rather than as a source of comparison. Thus another dialogue between the parts and the whole was established by thinking about one poem in the context of all the poems, as well as comparing the parts and the whole within the text. The shifting back and forth between the parts and the whole revealed new issues, and new questions that were then used to further interrogate the data (Benner, 1985).

The process of generating themes in hermeneutic phenomenology is less prescriptive and derived from the dialogue with the text (Grenz, 1996). van Manen (1990) regarded themes as the structure of experience. He argued that a theme is a focus of meaning that helps shape the phenomenon and describe the content of a notion. According to van Manen (1990) when we read or see something compelling then we experience the desire to make meaning. Phenomenological themes using this approach can be understood as providing structure to experience in order to elucidate meaning (van Manen, 1990). As the analysis progressed, two themes began to emerge from the data which was helping make sense of the poems. The themes were two different modes of being that the participants were describing. As I began to consider the mode of being the participant was in, this helped me to elucidate the meaning and structure of their experience. This began as a tentative hypothesis, but towards the end of the analysis there became a clear difference in the two modes of being of the participants. However, it did not seem possible to create any further themes within the modes of being since their experience was all interrelated and did not seem to fall into a specific structure. This is explored further in the analysis and discussion.

van Manen (1990) advises that once the themes are identified, they should be categorised into either essential or incidental. van Manen (1990) considered this an

important step as not all meanings are specific to a certain phenomenon. Thus essential themes are those that in their absence would leave the phenomena incomplete (Rapport, 2005). Since the two themes identified refer to two modes of being provide an overarching structure for the whole of the participant's experience, both themes were considered to be essential. The end of analysis was signalled when there was a coherent understanding of the phenomena which was free from inner contradictions (Kvale, 1996).

van Manen (1990) also suggested that the givens of the lifeworld (or the 'existentials') can also be used as a way of further interrogating the data. He suggested analysing the data using the following four existentials: lived space (spatiality), lived body (corporeality), lived time (temporality) and lived human relation (relationality or communality). Both the individual poems and the modes of being were analysed in relation to these existentials to provide a richer understanding of the findings. Also van Deurzen's (2002) four dimensions of human experience (physical, social, personal and spiritual) were also used to question the data and gain a deeper meaning. These are considered in detail in the following chapter.

For van Manen (1990) writing is not a process at the final stage of research, but instead is an essential part of the hermeneutic phenomenological investigation. According to his argument, writing fixes thought on paper and distances us from what we know and allows us to see more of what we want to know. Consequently, the analysis involved a constant writing and rewriting of reflections on the parts and the whole, showing a clear decision trail of thought. Each analysis of the participant, as well as the overall experience of the modes of being was written and rewritten several times. By noting themes and observations, a deeper level of understanding was achieved and allowed for a creative approach to writing the final text.

2.10.3 Reflexivity during the process of analysis

Beginning the analysis was quite a daunting process, particularly without any specific rules of how to achieve results. However, as I began to engage in "seeing" the text and moving between the parts and the whole, the hermeneutic circle came to life and I gained a deeper understanding of van Manen's (1990) hermeneutic phenomenology.

As I gained confidence I embraced the creativity of the approach and found myself drawing diagrams, writing and rewriting thoughts and constantly turning over the dialogue between the parts and the whole. Using poetic condensation aided the process of analysis immensely as I was able to read the rhythm of the text and hear the voice of the participant. Also I found that through the process of creating the poems, I was able to identify key parts of the interview that I might not picked up on if I had not been listening to the pattern of speech. Therefore I feel this method prevented me from imposing my judgements on what is important/not important in the text and instead listen to the narrator even more accurately. Finding the two modes of being was not what I had expected when I begun analysing the data, however I feel from analysing the data that this is an accurate interpretation of the individual accounts that give justice to the participant's experience. *(For all poems, see appendix xi).*

2.11 Limitations

The results of the study are unlikely to be generalisable since the sample is small and purposive rather than random. However, the purpose of phenomenology is not to find an objective "truth" that can be applied to all people, but instead to illuminate the unique human experience of a phenomenon. The same argument can therefore also be applied to the criticism that the study is unlikely to be replicated. Guba and Lincoln (1985) suggested when discussing reliability in a qualitative study that "dependable" is a more appropriate term. For a study to be dependable, another researcher following the decision trail would be able to draw similar (or not contradictory) conclusions. By keeping a reflexive diary and using transparency of process the readers of this study should hopefully be able to follow the journey of interpretation. Many authors criticize the validity of phenomenological research methods (Hyncer, 1985). Guba and Lincoln (1985) propose the term "credible" rather than valid, which is achieved when the study presents faithful descriptions of the data which the readers confronted with the experience can recognise. This was achieved by ensuring that all the conclusions were grounded in the data by continually comparing the hypotheses to the transcripts. Also credibility was maximised by corroborating the analysis with my supervisor.

INTRODUCING THE PARTICIPANTS

John[2] was a 73-year-old white-British gentleman who had a diagnosis of liver cancer. He said he had been living with cancer for the last 20 years. He had a partner, who came to visit him daily in his flat. John regarded himself as Christian but did not affiliate himself with a particular denomination.

Edith was a 68-year-old Caribbean lady who had a diagnosis of bowel cancer. This was her second experience of cancer. She had been diagnosed with breast cancer around 1989, but they had caught it in the early stages. She lived alone and had three adult children who came to visit her regularly. Edith considered herself to be a Methodist but stated that she had her own views on religion.

Bob was a 73-year-old white-British gentleman who had lung cancer. He said he had been living with lung cancer for the last few years. He was a widower and lived alone in sheltered accommodation. He said he did not have any visitors apart from his cleaner and his main source of social contact was the hospice. Bob said that he was not religious.

Kate was a 56-years-old lady with breast cancer and brain metastases. She had been living with cancer for the last ten years. Kate was white and born in Africa, where she grew up. She lived at home with her partner, and had a son and a daughter in their thirties. She said she had not decided on her religious status.

Lucas was a 76-year-old Jamaican gentleman who had liver and colon cancer. He had first been diagnosed with colon cancer approximately two years ago. Lucas was divorced and had recently moved in with his daughter. Before this he lived alone. Lucas considered himself a non-practising Roman Catholic.

Hatty was a 79 year old white-British lady with breast cancer. She lived with her second husband, and had one daughter and two step daughters, all of whom were grown up and living with their own families. This was Hatty's second occurrence of breast cancer; the first time she was diagnosed was in 1980. Hatty did not affiliate herself with a particular religion and considered herself to be influenced by all philosophies of life.

Jane was a 65-year-old white-British lady with colon cancer and liver and lung metastases. She was diagnosed around five years ago, which was initially operated on but then returned two years later. Jane's husband died four months prior to the interview and she was currently moving house because her husband's daughters were moving in. As well as three adult step-daughters, Jane had a son who was also grown-up. Jane regarded herself as "spiritual" and was a member of a spiritual circle.

Sandra was a 44-year-old British-Cypriot lady with breast cancer and bone and brain metastasises. This was the second time she had been diagnosed with breast cancer. The first diagnosis made in 1999 and the cancer had returned in June 2008. Sandra was divorced and lived at home with her 16-year-old son. She also had an 18 year old daughter who was at university. Sandra regarded herself as Greek Orthodox, but said she did not attend church regularly.

Box 1. A summary of the participants' background and context.

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[2] All names have been changed to protect anonymity

3.1 Overview

3.1.1 Two modes of being

Even during the process of interviewing I had noticed that there were two distinct ways people were describing their experience of meaning-making and "spirituality". Some individuals needed minimal prompting to discuss their experience. They described their views about the way the world or universe worked and where they saw themselves in the bigger picture. Their narrative was more of a summary of their lives and their focus was on how death fitted in to this journey. Other participants did not really seem to connect with the research question and required a lot more prompting to reflect on their purpose or meaning in life. These participants focused more on how they were getting on with their day-to-day lives given the limitations of their illness, and went on to discuss the importance of relationships in their lives. During analysis I uncovered two modes of being; the "everyday mode of being" and the "transcendent mode of being", which reflects these two ways of interacting with the world. These modes of being are not exclusive, but instead represent the way the individual is relating to their environment as they approached their death. Thus individuals can switch between these modes of being, which can be dependent on their circumstances as will be discussed later in this analysis.

The results suggested that "spirituality" was a product of interacting within the individual's world, revealing the intersubjective quality of their experience. As mentioned previously, intersubjectivity refers to the notion that we are always related to others and our environment and never completely separate (van Deurzen and Kenward, 2005). This concept is fundamental to the philosophy of existentialism, pioneered by Husserl (1931; 1967) and Merleau-Ponty (1962), who both argued against dualism and considered humans as always being both self and other. Therefore according to existential philosophy, humans can not be considered in isolation and should be viewed in terms of their interactions with other people or the

environment (Spinelli, 2007). However Spinelli (2007) argued that this is difficult in Western culture since the English language enforces a split between subject and object. May (1983) commented that in Eastern languages adjectives always imply the "for-me-ness"; to say "this flower is beautiful" means "for me this flower is beautiful". However Western language imposes a dichotomy between subject and object, and thus saying "the flower is beautiful" implies that the flower is objectively beautiful and has nothing to do with ourselves.

To overcome the language barrier, Heidegger (1927; 1962) proposed the term Dasein, or being-in-the-world, to reflect the intersubjective qualities of human beings with other people and their environment. By using this term, Heidegger (127; 1962) implies that we are so much of a part of others that we still relate to them in their absence; the self we consider "I" can never be detached (van Deurzen and Kenward, 2005). However, Spinelli (2007) argues that the term "Dasein" too static and does not reflect that our relationship with the world and others is a process rather than a 'something'. Consequently Spinelli (2007) proposes the term "*worlding*" to reflect the verb-like quality of intersubjectivity from an experiential perspective. Thus the term "*worlding*" refers to *"the ongoing, ever-shifting, process-like, linguistically elusive living of being"* (Spinelli, 2007; p. 18).

Since *worlding* is ever-changing, Spinelli (2007) argues humans have to impose structural limitations on *worlding* in order to reflect on and describe their experience. He termed this structure the "*worldview*". The worldview humans impose on *worlding* appears to be fixed, but this can also change through circumstances or human-imposed variables (Spinelli, 2007). Using this theory, the two modes of being found in this analysis can be understood as a structural model imposed by individuals which allows them to make sense of their world. However, as Spinelli (2007) suggests, these structures can change as a consequence of the ever-evolving world and person, which are supported by the findings in this research.

3.1.2 The appropriateness of the term "spirituality"

Within these two modes of being there was an important phenomenon emerging from the interviews. However the dilemma lies in whether to continue labelling this phenomenon "spirituality" or to consider using different terminology. In the everyday mode of being, meaning was derived from interacting with friends, family, society and nature and the individual's roles in these relationships. No one in this mode of being used the term "spirituality", raising the question how useful is the term when the individuals do not relate to it? This was particularly evident by the short interviews and the confusion from participants as to what I was asking about. However this is not a reason to abandon the phenomenon altogether but presented an opportunity to revise the use of terminology for people in this mode of being. Therefore I argue "spirituality" is not appropriate for individuals in the everyday mode of being and propose that the term "belonging-in-the-world" is more suitable.

For individuals in the transcendent mode of being, participants connected with the word "spirituality" and did not need much prompting to discuss their experience of the phenomenon. They found meaning in separating themselves away from the material world and unhelpful social interactions and experienced "spirituality" in the inner world where time and space were not relevant. In the inner world participants transcended their immediate situation and considered their existence in the context of the whole. I argue that the word "spirituality" is still relevant in this mode of being.

An in depth analysis of the experience of "spirituality" and meaning-making in each mode of being will follow. When analysing the data I found it helpful to conceptualise the data in terms of van Deurzen's (2002) four dimensions of human experience. These include: the physical dimension, referring to embodiment in the physical world; the social dimension, which includes relationships and interactions; the personal dimension, meaning the selfhood and private world; and the spiritual dimension which refers to how we understand the world, human living and ourselves. van Deurzen (2002) did not intend for these dimensions to be exclusive since all facets are interwoven. Similarly, within the context of this analysis the dimensions are used to facilitate the discussion of experience rather than to represent themes.

Furthermore, although van Deurzen (2002) has named the last dimension "spiritual", the results show that the experience of "spirituality" and meaning-making plays a role in all the dimensions of experience.

During the process of analysing the interviews and writing about the two modes of being I became wary that the everyday mode of being could be interpreted as a less developed way of being in the world as the transcendent mode of being. However my intention in the following exploration of the two modes of being in the world is not to impose a judgement on which mode is 'better' but instead to illuminate the two ways that people interact with the world. This point will be revisited in the conclusion.

THE TWO MODES OF BEING

3.2 The Everyday Mode of Being

3.2.1 Physical Dimension

The way in which we are thrown into the world is first and foremost as physical bodies in the material world (van Deurzen and Arnold Baker, 2005). Thus van Deurzen's (2002) physical dimension refers to bodily actions in relation to objects. van Deurzen's (2002) dimensions were developed from Binswanger's (1963) three modes of being-in-the-world. The physical dimension correlates with the first mode, *Umwelt*, which is the realm of action within our environment (Binswanger, 1963). The physical dimension was very important for individuals in the everyday mode of being. The participants were chiefly concerned about interacting with their environment and completing daily tasks. Their cancer had changed their mode of being-in-the-world as they struggled with the limitations of their physical body. van Deurzen and Arnold-Baker (2005) noted that often our identity is tied up in how we feel about our bodies which was true of participants in this mode of being. When asking participants what life was like for them at the moment, the first topic discussed

was their ability to interact with the physical world. The content of the interviews were focused on how their illness had affected their mobility, the pressure of going to endless hospital appointments and their capability to go out and interact with others.

What is life like for me at the moment?
Well, with the knees they are not very good.
If I want to have a shower
I got to have someone to help me

I can go down the stairs and come up the stairs
With the help of the railings
I move around in the house ok
If I have to go out I can do short walks but I can't do very long walks
Lucas

Reviewing what individuals could and could not do therefore became extremely relevant in this mode of being. The participants drew comparisons between how life was before they were ill and the current time as they came to terms with their new way of being-in-the-world. The limitations from having cancer made them feel frustrated as they struggled to maintain their usual lifestyle. This is inline with van Deurzen's (2002) hypothesis that emotional well-being is correlated with the way we feel about the physical dimension. The cancer felt like an enormous burden that was taking all their time and energy when they would prefer to be getting on with life.

But I've worked as a nurse for 45 years
So I've had a lot of people come through my hands
And my head
And I've loved it all…

…I had to resign last year, because they kept my job open for me for two years
They'd call: coming back? coming back? coming back?
65 already – you coming back?
No, I can't now, there's too much other stuff
Jane

According to van Deurzen (2002) the physical dimension is where we think about how our body is experienced in the world. This is a core concept in van Manen's (1990) existential of "lived body", which relates to how we interact with others physically in the world. For participants in the everyday mode of being, their body was constantly changing and how they might experience symptoms in the future was uncertain. They were all currently in treatment and wondering what might happen next and how this would affect their day-to-day living. Embodiment was an important consideration for Merleau-Ponty (1962) who regarded the body as the vehicle for being-in-the-world. Thus the body is our way of belonging to the world (Merleau-Ponty, 1962). For these individuals their relationship with their body and therefore their environment was no longer secure. Since embodiment was a main feature in the interviews I became more aware of my own body and how I take for granted what I am able to do. Yalom (1980) suggested that people who have chronic illnesses go through a process of disidentification as a consequence of no longer being able to do the activities or fill the roles they used to. He demonstrated this to a class by asking them to reflect on what life would be like if you could not fulfil one of the main responsibilities in your life. I felt myself reflect on this during the interviews and realised that there was a sadness and anxiety the participants were communicating about their uncertain future in the physical dimension.

I wanted to go again

Now that I'm still able to travel
Cause I don't know how
Because it's in my spine I don't know how it's going to be
If I'd be able to travel or not
Sandra

For Lucas and Jane, this insecurity was associated with the prospect of going back onto chemotherapy. They both expressed dread about having the treatment and worried about how they would cope. It seemed that going back onto chemotherapy would completely disconnect them from the world for the duration of the treatment. This correlates with McGrath's (2004) study on people who were in remission from

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haematological cancers. They described being so overwhelmed by the burden of chemotherapy that they could not reflect on life until the treatment had finished. Therefore it seemed that for Lucas and Jane chemotherapy would lead to a greater emphasis on the physical dimension without much energy left for the social, personal and spiritual dimensions.

So I've got to go back now onto ghastly old chemo which I don't do very well
I hate it, it's horrible.
I had a lot of trouble last time
Jane

Embodiment is also concerned with how we physically experience others-in-the-world (van Deurzen, 2002). Due to their physical limitations the individuals commented that they spent large periods of time alone. Consequently Sandra and Bob commented that just having someone physically in the room was a meaningful connection. They did not necessarily want to talk about their experience of life but instead valued having company. This was reflected during the interviews. All participants were enthusiastic to meet but did not want to elaborate greatly on how life was like for them at the moment leading to shorter interviews of about 30 minutes. I noted in my diary that after finishing the interview with participants in the everyday mode of being, I was very aware that I was leaving them alone and felt reluctant to go.

Once I was really really depressed on Saturday
And she came round
And we went for a walk in the park

I didn't even talk about what I was depressed about
Didn't need to
By the time she came up I was so much better
I was fine after that
Sandra

Jane was comforted by the presence of her husband even though he was not physically there. She spent a large part of the interview telling me about his history

and their relationship. Even though he was no longer alive, her conversation evoked his presence into the room. Jane's interview was the only longer interview, which I felt was due to her distress and need to talk this through with someone. She gave me a huge hug at the end of our conversation which I felt expressed her need for physical contact. I felt guilty leaving her at the end of the interview as I withdrew my physical presence as well.

I just have to believe that he is there for me now but I can't touch him
Jane

The physical dimension is also concerned with death, since this is the end of the physical body in the world (van Deurzen, 2002). None of individuals discussed what death might be like in the interview. This was reflective of their internal processing of death since any time they thought about dying they tried to distract themselves. Both Sandra and Lucas regarded these thoughts as unhelpful since there was nothing they could do about dying. Their main priority was focusing on what they can do physically. Although Jane said that death would be a relief I got the impression from the very emotive interview that she was scared. Bob did not discuss this topic at all during the interview.

I try not to think about the cancer
Too much
Well it do cross my mind at times
But I try not to worry about it too much

Because worrying not going to help it
So I try not to
Whatever treatment they want to give me I make sure I take it
So not bother me

I cope with that
Lucas

Reflecting on van Manen's (1990) existential of lived space, it appeared that the world of the individuals was small and contained in this mode of being. Merleau-Ponty (1962) maintained that notion of spatiality is not necessarily geometrical space but rather to a spatiality of situation. Life for participants in this mode of being was about their homes, the hospital and walking around the local area. Lucas and Jane commented that nature was very important for them, which for Jane was the woods outside her house and Lucas was his garden. However, unfortunately for Lucas his symptoms meant that he was no longer able to do the gardening. He said this with great sadness in the interview as his lived space became smaller and a large part of his identity and enjoyment had gone from life.

I used to love to do gardening
I used to do my garden every year
But I couldn't do it this year

And I do love that
Lucas

For participants in the everyday mode of being, the experience of "spirituality" and meaning-making was associated with *doing* things and belong to the world. This correlates with Watt's (2009) finding at the cancer drop-in that doing things and being an active member in the community was very important for the participants. By carrying on with their every day lives despite their limitations, individuals in the everyday mode of being felt a sense of belonging in the physical world and being physically present with other human beings. The progression of their symptoms and having chemotherapy threatened their belongingness to the world. Death was not something important to think about since there is nothing they could *do* about their death.

3.2.2 Social Dimension

van Deurzen (2002) described the social dimension as the emotional relations to others. This was inspired by Binswanger's (1963) *Mitwelt* which is the mode of being with others. Heidegger (1927; 1962) argued that being-with-others was just as important as being-in-the-world. Within the everyday mode of being, individuals

acknowledged the importance of relationships in their lives. Without relationships experience was meaningless. This relates to van Manen's (1990) existential of lived human relation, which postulates that human beings search for a sense of life's meaning and purpose in their experience of the other. All participants mentioned that being lonely was a source of distress and that connecting with people made them feel happier and more secure. Yalom (1980) discussed existential isolation as *"the unbridgeable gulf between oneself and any other being"* (Yalom, 1980; p.355). According to Yalom (1980), death makes one fully realise the extent of their isolation since no one can die for us or with us. Perhaps therefore individuals in this mode of being were reaching out to others to reduce the expanding gulf between themselves and others.

What is important in life?
Well more than anything
Companionship.

…If you've got a bit of companionship
It breaks the monotony
Makes a hell of a difference.
Bob

There were certain relationships that each of the participants identified as important for providing support and company. The individuals valued relationships that recognised them as a whole person and not just a person with cancer. Connecting with someone as a whole person was also an important facet of spirituality in McGrath's (2002) study. The people who were central figures had not necessarily always been their in their lives in the same way. This fits with van Deurzen's (2002) observation that the way we find ourselves in the world with others varies from moment to moment. The participants found new relationships, grew apart from old ones and found different ways of interacting with people who had always been in their lives. For Sandra, her sister was important in her life. She found her parents were treating her like a child but her sister was still treating her like an adult. Sandra spoke of this relationship as something positive that had come out of her experience of cancer.

I've got a lot closer to my sister 'cause we speak to each other every day
Before it was once a week or and now it's every day we phone each other up
Which is nice
Sandra

Lucas had the support of his family. He had always had a good relationship with his family and they were there for him now despite being in America. He found a new relationship with his ex-wife who had been supportive and his daughter helped him interact with his physical world by taking him out.

Because I have a daughter there
She's good
She's very good to me

And my grandchildren are very close to me as well.
They do what they can for me
And even my ex-wife
She's pretty close to me as well!
Lucas

Jane had a number of friends that who were important in her life that she had gained at other crisis points, such as going through a divorce. Her housekeeper was now a valued connection since becoming ill with cancer. The housekeeper had originally come to help out around the house, but as time went on they became a lot closer. After Jane found out she had to go back on chemotherapy, their relationship evolved and the housekeeper offered to care for her in this difficult time.

And she said well I don't think I can leave you if you're going on chemo
I want to come with you
To look after you

…So that will be alright it doesn't matter.
She's a lovely girl, lovely girl,

So there's somebody there
Jane

Bob was particularly adamant about the role of other people in his life. As a single man living on his own, he felt life was pointless if there was no company. He had a special relationship with his cleaner, who would do anything for him. They would have arguments but she would always come back, and he knew he could rely on her whatever happened to him.

I mean she's a marvellous person
I could never live without her
Bob

When viewing life through the everyday lens, individuals became frustrated that their illness stopped them from going out and socialising more. They felt limited in what they could do and disconnected from other people in their world. Thus their view of the physical dimension very much affected their social dimension as well. Lucas was no longer able to write letters to his brothers, Jane was busy going to hospital appointments and Bob and Sandra were limited in how often they could leave the house. McGrath (2002) similarly found that participants felt they had lost connectedness with the intimate world when diagnosed with cancer.

What is life like for me at the moment?
Well at the moment
It's quite tedious being by myself all the time
I don't see nobody
Apart from my cleaner comes in twice a week to see me.

....I was absolutely cheesed off sitting indoors by myself all day.
I used go down to the betting shop
Sometimes you might win a few pounds, other days you lose a few
Just for the companionship

Since this breathing's got worse

I haven't been out the house

Bob

Having company for individuals in this mode of being was both a distraction from their thoughts and a comfort. Given that they were not able to interact with the world as much as they would like to, having a connection with someone who was, made them feel like they still belonged to the world.

And I knew she [the housekeeper] *was intelligent, and she talk about politics*
And social things
And art and books and literature,
She's going and seeing things and doing things
'Cause you know when you're not working who is around you to stimulate your life?
Jane

As a consequence of being more limited in the world, it was important for individuals in this mode of being that they were also useful to other people. Sandra was taking out her children for weekend trips, Jane was helping out other people in need and Bob was bringing things in for charity. Thus being-with-others was reciprocal and not just about receiving social support off other people. Watts (2009) also found that individuals at the cancer drop-in valued the opportunity to reciprocate helping others who were also facing difficulties and was an important part of their experience of "spirituality".

For 7 – 8 weeks I've been bringing little boxes of ornaments…
…She's always grateful for it
And I'm sure the shop is grateful for it

So I'm happy enough.
It gives me a point in life
I'm doing something to help somebody
Bob

Individuals looking at life through the everyday lens were extremely grateful for their hospice. They spoke about how other patients and staff understood their needs and made them feel welcome and part of the community. This was seen as a special place where the individuals could be themselves and feel a valued member of a group and not a person with cancer. The conversations they had with staff and patients made them feel like someone knew exactly what they were going through. This validated their feelings and gave meaning to their experience. The way they spoke about the hospice suggested that trying to connect with people who did not have cancer was more challenging. Thus the hospice was a cherished source of intersubjectivity.

Coming here helps because you meet other people
You know that are suffering just like you.
And you see some of them that are worse
Often than myself

And when you meet with other people who have it as well
You can talk
And they can tell you how they feel
And you can say how you feel
Lucas

As well as good relationships, the participants were thinking about the relationships that did not have a positive influence. Because they were reliant on other people to visit them, they felt frustrated when people let them down. It felt like their well being was in someone else's hands.

Once you're in your flat, you're in your flat and that's it
Unless anybody makes a point to come and see you

You don't see nobody
Bob

McGrath (2002) similarly found that participants with haematological malignancy had little tolerance for others, particularly those complaining about minor illnesses or

those who only see problems and not blessings. In both this study and McGrath's (2002) research, lack of support from friends caused a lot of distress for individuals with cancer.

I don't stand for nonsense
So if people don't phone me up I don't bother phoning them up
It up to them if they want to phone me up or not
Sandra

Both Jane and Bob were struggling with feeling abandoned by their children. This had a very negative impact given their illness and the importance of connection at this stage in their lives.

I've got four step daughters
And they don't care two monkeys.
But if I was to win the lottery this week
They'd be on the door step tomorrow morning to see what they were going to get
Bob

Jane had to rely on her step daughters for financial support following the death of her husband. Their lack of cooperation was particularly hurtful given that she was not going to be in the world for much longer.

Apparently they were going to look after me financially but it's all a bit up in the air.
…But I was a little bit annoyed at first when this came out and they knew that I
        wasn't going to live very long.
And I thought well that's a bit mean
Jane

Interestingly none of the individuals in this mode of being had a partner. Lucas had been divorced although he still had the support from his ex-partner, Bob was a widower for nineteen years, and Sandra was also divorced. They felt like not having a partner was like something was missing.

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I do miss not having a man by my side

…I just feel like I wish I had somebody with me

Sandra

Jane regarded not having her husband by her side as losing the meaning in her life. Thus having a partner was regarded as an important source of meaning and purpose in this mode of being.

How long ago did he die?

September

So one of the reasons for living has kind of just gone.

….It's just it loses its meaning doesn't it a bit.

When you've lost the one you love.

Jane

Having a relationship was an important source of meaning and "spirituality" in the everyday mode of being. Interestingly Watts (2009) also found "spirituality" was largely associated with connecting with family and friends as well as wider social networks. The quality of these relationships was fundamental, since participants reflected the need to have people connect with them as a person and not a patient. By interacting with their family, friends or the hospice they retained their sense of belongingness to the social world, reducing their sense of isolation. Baumeister and Leary (1995) suggest that the foundation of all relationships is the 'need to belong', which appeared to be true for these participants.

3.2.3 Personal Dimension

van Deurzen and Arnold-Baker (2005) describe the personal dimension as the sense of self which has to be acquired by each individual. This correlates with Binswanger's (1963) third mode of being, *Eigenwelt,* which is our private world that we create by ourselves. Writing about the personal dimension was more challenging than the physical and social dimensions in the everyday mode of being. The participants did not make explicit reference to their private world and so reflection on

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this dimension required more interpretation on my behalf. Therefore this section could perhaps be more open to debate.

In the relational world there exists a tension between standing in our own right and merging with others-in-the-world (van Deurzen and Arnold-Baker, 2005). Standing as a person in our own right can be hard and requires solitude (van Deurzen and Arnold-Baker, 2005). However, individuals in the everyday mode of being appeared to be reliant on others to gain their sense of self. Being with others and engaging in activities in the physical world allowed them to reflect their characteristics and personalities. Thus for the individuals in the everyday mode of being the personal dimension was overlapping with the social and physical world. Solitude seemed to imply loneliness and the individuals seemed to strive for company as often as possible.

I was absolutely cheesed off sitting indoors by myself all day
I used go down to the betting shop
Sometimes you might win a few pounds, other days you loose a few
Just for the companionship
Bob

They talked about "being strong" so they could keep their body going, and therefore maintain their selfhood. Similarly McGrath (2002) found individuals with haematological malignancy demonstrated "spiritual strength", which referred to the person's ability to deal with the demands and challenges of serious illness.

And even now
Even though the doctors have said
Well the Macmillan nurse said that it might have been my last Christmas
I feel strong enough, I reckon I can see the next Christmas
Sandra

Part of being strong was accepting the circumstances around them and getting on with it. Even though the prospect of more treatment was harrowing, individuals in this mode of being did not question the medical advice and took on a stoic attitude.

Choices about treatment were made by the medical professionals and the individuals prepared themselves for whatever would be thrown next to them in their journey.

I know it's there
And if the doctors can't help it
Then I won't be able to help it

So I just accept the treatment
Whatever treatment they give
I accept that
Lucas

Part of the personal dimension is about defining our lives and discovering the boundaries of our freedom (van Deurzen and Arnold-Baker, 2005). Individuals in this mode of being did not see themselves as having any choice, and therefore did not regard themselves as having any freedom. They felt like the limitations of their physical body reduced their choices of how to live within the physical and social world. Instead they tried get on with their usual lives as they are the best they could, but since they were not able to maintain all their usual activities they viewed their freedom as becoming more and more limited. Freedom is an important concept in existential therapy and is one of Yalom's (1980) "givens" of existence. However, freedom can only be exercised within the limitations of our "throwness" (Spinelli, 1989). For individuals in the everyday mode of being their "throwness" as a person with advanced cancer meant they felt they experienced less freedom compared to their previous healthy selves. However, in existential theory there is another freedom: the freedom to interpret a situation (Spinelli, 1989). This was perhaps not a consideration for individuals in the everyday mode of being since they were focused on *doing* things rather than reflecting on their interpretation of the situation. Consequently their perceived freedom was limited and choice was viewed in terms of physical capabilities.

And I'm putting one foot in front of the other because I don't have any choice
Jane

For individuals in the everyday mode of being the personal dimension was largely inseparable from the social dimension. Tacey (2003) maintained that the self only comes to know itself in relation to the other which seemed true of participants in the everyday mode of being. However there was no mention of a private sense of self that was maintained in the absence of other people. Watts (2009) concluded that "spirituality" is maintenance of the congruent 'self' which is established through interpersonal relationships. As found in Watt's (2009) research, the individuals in the everyday mode of being tried to retain their personhood through active relationships. In addition, their experience of "spirituality" and meaning-making in this dimension was associated with gathering their inner resources to carry on with life. Their perceived lack of freedom meant that they needed to be strong to face the physical demands of their existence and carry on with their physical interactions and social relationships in order to prevent the dissolution of the self.

3.2.4 Spiritual Dimension

van Deurzen (2002) added a fourth dimension to Binswanger's (1963) three modes of being called *Uberwelt*, or the spiritual dimension. van Deurzen (2002) described the spiritual dimension as how we make sense of the world and create meaning. The spiritual dimension is therefore how we understand the world, human living and ourselves with reference to our culture, time, society and history (van Deurzen and Arnold-Baker (2005). Individuals created meaning in the everyday mode of being by keeping themselves busy. They were all trying to get on with life, get around with limitations. It was important for all of them to continue being mobile and do as much as they can both physically. I addition it was equally important to keep their mind active and up to date with what was happening in the world.

And trying to keep myself amused, watching television
Or doing something culturally inventive
Or something I can learn something from
Which means that the terrestrial channels aren't doing anything
Just have to keep your mind going with something else
Jane

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An important facet of the spiritual dimension is purpose. According to Weixel-Dixon and Strasser (2005), humans need purpose to make living comprehensible and worthwhile. Yalom (1980) argues that purpose and meaning are not interchangeable despite them often being used synonymously in the literature. Purpose relates to intention aim or function and having purpose of function is connected to having a reason for existence (Yalom, 1980). Individuals within this mode of being still felt they had a purpose which was concerned with maintaining relationships with family friends and the community. Thus the spiritual dimension overlapped with the social dimension. Related to this was Watts' (2009) finding that citizenship was a primary factor in their experience of "spirituality". A number of the individuals in Watts' (2009) study were active in their community which gave them a sense of purpose and helped confirm their self worth. Watts (2009) concluded that *being* was *doing*, and mainly *doing for others*. In the current study individuals in the everyday mode of being had roles they wanted to fulfil, mainly for others, that kept them going. For Sandra this was looking after her children.

I try and do things with the kids
My son's 16 and we went to the zoo on Thursday because he was on half term
And we had such a fantastic time
It was really nice

On his 16th birthday
It cost me an arm and a leg
But I hired him a mini bus, took all his friends to paintballing
So things that they can all remember together
Sandra

For Bob this was being part of a community and going to the hospice as regularly as he could. His trip to the hospice made all the difference for him. He liked the people there and they liked him. He was currently helping clear his neighbour's house by bringing in items for the charity shop. His purpose therefore was very much overlapping with the social dimension

[name] would tell you for 7 – 8 weeks I've been bringing little boxes of ornaments

that have come from my neighbour's place when she moved
for the charity shops...

...So I'm happy enough.
It gives me a point in life
I'm doing something to help somebody
Bob

For Jane this was looking after people. She was a nurse in her career and enjoyed looking after children. She also looked after her son's ex-girlfriend when she needed some help. Looking after others had been her identity and meaning throughout her life and was equally important to her now.

And I know I'm here to do service
And always have been
And then when the job's finished I'll go

And what does that service mean?
That we're here on the planet to look after other people
And it can be in anyway we like
Sitting here talking to you
Jane

For Lucas this was interacting with nature and maintaining his independence. Although he could not garden any more, he was still pleased about going for short walks and getting about on his own.

Some months ago I was pretty weak
But since I started to do the exercise here and that helped
Now and again I manage to get to my GP
It's about 5-600 meters from here I'd say to get there

So it's a fair walk
But I manage it

But sometimes I have to stop
Take a blow and then go again
Lucas

Purpose infers temporal dimensions since it refers to the person's future direction (Yalom, 1980). van Manen (1990) proposed that lived time was another given life existential. This is also an important facet for van Deurzen's (2001) spiritual dimension. Heidegger (1927; 1962) proposed that time is the most significant aspect of human being, as suggested by the title of his book *Being and Time*. Human existence for Heidegger (1927; 1962) is temporal; we are motivated by a future which allows us to realise our possibilities. Heidegger (1927; 1962) referred to time as ecstasies referring to the past, the present and the future. van Manen (1990) maintains that these three temporal dimensions cannot be considered in isolation. As a person evolves, their past and present change in light with their present. The immediate reality is the only place where past, present and future merge as a single reality. Since all individuals in this mode of being felt strongly about their purpose, the future was still relevant to them despite not knowing how long they were going to be alive. Thus the future may be time limited, but they were still driven towards a goal which moved them forward in time. Participants in the everyday mode of being were therefore viewing time in a linear fashion.

But I have really realised that,
Well the Macmillan nurse told me to enjoy my Christmas this year because it might be
        my last Christmas
And it's got me thinking
So I've got my Will all in order
Got me thinking I won't be here in a few year's time

So make memories now basically
Sandra

It is important in existential psychotherapy to look at how a person perceives time. The phenomenological understanding of time refers to time that seems to speed up in enjoyment and slow down in periods of boredom or anxiousness (van Manen, 1990).

Time seems to have slowed down for these participants. Boredom was a factor when they were on their own.

What is life like at the moment?
Totally boring
I'm stuck here indoors
Sandra

Since individuals had realised the implications of being-towards-death, time was in the forefront of their mind since they could not deny their temporal limitations. Time spent not doing things was seen as wasted time. The interview also felt time pressured. They said what they wanted to say quickly and succinctly. All participants did not want a second interview, perhaps because this would be seen as more time wasted given that they had already told me about their experience. This was reflected generally in the participants' descriptions of events and the interview experience rather than captured in a quote.

Thinking about political and ideological ideas is important in the spiritual dimension (van Deurzen, 2002). The spiritual dimension allows us to think about good and evil, how we see the world and what we would like to see (van Deurzen and Arnold-Baker, 2005). The individuals in this mode of being viewed politics on a concrete individual level as opposed to thinking abstractly about the whole world. They commented on their immediate experience, such as other people's "selfish" behaviour. Lucas discussed he does not judge people in the colour of their skin and others should do the same. Bob believed that charity should begin at home and was concerned about other people in his local area. He was not concerned about other countries, such as Africa, and thought that charity should be prioritised in the immediate neighbourhood. Seligman (1990) correlated increased feelings of hopelessness to the alienation of modern society. He observed that "spirituality" reduced depression rates of the close knit community of the Amish compared to western society. Given that individuals in this mode of being felt disconnected from society, it seemed that their main concern was increasing the community spirit in their local area.

There was a program on TV last night

I think somewhere in north Finchley

One big estate will be without electricity and gas, water for the rest of the year right
over Christmas

And yet they send all this money overseas

Instead of getting this country organised properly.

I mean I believe in charities to a certain extent

But the truth is

That charity always begins at home

Bob

According to van Deurzen (2002) values and beliefs are an important facet of the spirituality dimension. In discussing beliefs within the interview all the participants in this mode of being thought the word "spirituality" was making reference to religion. Consequently the individuals discussed how religion had affected their life. All of the participants said that they had they same beliefs now that they had throughout their lives. Bob had never regarded himself as religious and still does not now.

What are my beliefs?

I've never been religious

…The last time I had anything to do with the church

Was when my second wife died

Bob

Lucas was a non-practising Roman Catholic, and continued not to go to church. However, he did start praying just in case it did help his treatment, but he did not hold out much hope for its success. McGrath (2002) also found that individuals who claimed not to be religious spoke about prayer. In this study one participant found this helpful, and for another they found this confusing. Lucas seemed to be a bit confused about why he was praying, or who he was praying to. However, his attitude seemed to be "hedging his bets" just in case prayer did work.

I must admit I say my prayers when I go to bed at night
I do things like that...

... What sort of effect does prayer have for me?
Well, I don't know it helps
But I still try!
It's like everything else
You don't know if it helps
Lucas

Sandra had always been religious, but did not attend services. Religion for Sandra was more about connection to others than rituals and practices. Some of her family members were priests and so she wanted to thank them for their support. She also received comfort from a priest who gave her permission to cry. Thus for Sandra her religion was an important source of social contact, and gave her the physical presence of a person there if she was distressed.

The first time I cried after being diagnosed with the secondary cancer
Was when I went to another monastery in Colchester
Just so I could get blessed by the priest
And basically have all my sins removed, or whatever it's called!

I said to the monk "oh please I'm so sorry I cried"
And he said "what are you saying sorry for?
You're allowed to cry
I cry all the time, you're allowed to cry"

And he really made me feel like you know
That I am allowed to cry if I want to
And because he said it
I don't cry anymore!
Sandra

For Jane her spiritual circle gave her company and believing in a higher being lead her to feel she was being looked after. Her friends from the circle would ring her regularly and see how she was doing, and she knew that people were concerned about her wellbeing. Yalom (1980) argued that entering a relationship with higher being can counteract existential loneliness, particularly in the face of death. Given that Jane had recently lost her husband, her spiritual circle provided her with a lot of comfort and a connectedness to other people.

I've got circle meetings..
..But they're all very good
they're there when I want them
and even there when I don't want them.
Jane

The experience of "spirituality" and meaning-making in the spiritual domain was also overlapping with the personal and physical domain in the everyday mode of being. Keeping busy and doing things contributed to the experience of "spirituality" in this domain. The individuals had a strong sense of purpose and were driven by future goals. The awareness of temporal limits made their purpose more pressured, and idle time was seen as wasted time. This supports the finding discussed in the personal dimension that individuals did not want to spend time on their own reflecting on their inner world. Politics in the everyday mode of being was about the immediate and the concrete. Thus they were concerned about how people's behaviour and social policies affected their immediate world rather than thinking about the world as a whole. Perhaps because they were having a difficult time negotiating their physical and social dimension they were more concerned with the here and now. Politics was about their lived reality rather than an abstract discussion. Religion was also about concrete experience.   Being religious for individuals in this mode of being was about rituals and social support.

3.2.5 Summary

In terms of Spinelli's (2007) theory of imposing a 'worldview' on the ever-changing interrelated 'worlding', it appeared that participants in the everyday mode of being

had a small and rigid worldview. Spinelli (2007) discussed sedimentations as the fixed pattern of rigid dispositional stances. More rigid sedimentations mean more boundaries between the self, world and other, leading to more security and more meaning, but less flexibility. Individuals in the everyday mode of being maintained the same worldview from before they were ill and struggled to relate to the world as they had done previously as a result of the cancer. Consequently individuals in the everyday mode of being felt that they had less freedom than before and their options were more limited as they tried to create meaning in the same way they had done before they were ill. They felt their connection with the world was becoming more and more tenuous as they became more ill which appeared to lead to anxiety and sadness.

The experience of "spirituality" and meaning-making in this worldview cut across all of Van Deurzen's (2002) dimensions for participants in the everyday mode of being. There was a particular emphasis on being able to *do* things, especially for other people. Their cancer had changed their body, and thus their usual way of being-in-the-world, which meant they felt disconnected from their social and physical sphere. Thus individuals described being "strong" despite their symptoms, and continuing with their roles and day-to-day activities. They felt they did not have any choice but to carry on and therefore it was important to try to maintain their usual way of being-in-the-world as much as possible. Connecting with other people and having genuine reciprocal relationships was an important component of their experience of "spirituality" and meaning-making. Their sense of self was dependent on these relationships as they tried to resist depersonalisation from the cancer. Individuals in this mode of being felt time pressured and tried to make the most of every day. Their political beliefs were based around community needs and religion was seen as a source of support.

Only Jane described her experience as "spiritual", which she used in the context of having something with her so she is not alone.

But then again it's the spiritual side, you're not alone

I'm not alone

Because I'm being looked after

Jane

The rest of the participants thought "spirituality" was in reference to religion and many seemed confused about what I was asking them to describe in the interview. Nevertheless there appeared to be an important phenomenon emerging from the interviews associated with belonging to the world in order to maintain their sense of self and find meaning. The findings seem to closely resemble Watt's (2009) conclusion from observing individuals at the cancer drop-in that "spirituality" was about connecting to family, friends and wider social networks. For these participants having a role in their community was essential for their sense of self. None of the participants referred to this as "spirituality" but Watts (2009) concluded that these factors were so entwined with their everyday being and personhood the phenomenon was "spiritually significant" (Watts 2009). However given that participants in the current study did not connect with the term "spirituality" and individuals in Watts'(2009) research did not mention the word "spirituality" over the 15 month period of data collection, I feel that the term is not useful, and perhaps even a hindrance, to people in the everyday mode of being. Thus in agreement with Walter (2002) I feel that spiritual terminology should only be used with people who find this discourse helpful. However, there is still an important phenomenon emerging from the data that should not be ignored due to difficulties with the terminology. I propose that the term "belonging-in-the-world" captures the essence of the phenomenon and would be more appropriate than "spirituality".

3.3 Transcendent Mode of Being

3.3.1 Physical Dimension

There was less emphasis placed on the physical dimension, or *Umwelt*, for individuals in the transcendent mode of being. Reflecting on van Manen's (1990) existential of lived body, these individuals had separated their mind from their body. The participants in this mode of being found that their bodies had become useless and

were not helping them to interact with the physical world. All the participants in this mode of being had stopped having treatment. I saw Edith on the ward as she was having her medication reviewed, but she was not having any further chemotherapy or invasive treatments. The individuals in this mode of being had decided not to receive any more treatment since their bodies were not responding and it was only making life more difficult. Consequently individuals found other ways of being-in-the-world without relying on their bodily 'vehicle'. Since the physical body is how we 'belong to the world' (Merleau-Ponty, 1962) the participants in this mode of being felt like they were no longer in the world the same way that they used to be. Kate described this as being in the "ill world" where there is no body. For Kate the physical world was the "well world" where people belong when their bodies are still functional. Nevertheless, there were still times when the individuals in the transcendent mode of being needed to use their bodies to fulfil obligations, such as going to hospital appointments. When being forced to partake in the physical world they felt frustrated and like death, or the relief from their body, could not come soon enough.

When I've being extremely ill
I've spent days in total silence
And been taken to being a dot in the universe
Actually that's all with no body

I have no interest in my body
It's of no use to me now at all
Except to try and walk about the place which is very difficult
Because it's pretty useless

Unless I don't go out
I'm not there at all in my body
I'm more in my head
It just doesn't interest me
Kate

Since interacting with the everyday physical world did not hold as much meaning for participants in the transcendent mode of being, they thought about how they fit into

the bigger picture. Their focus on the world had zoomed out and the emphasis was no longer on individual experience but instead objectively viewing themselves as a tiny piece of the whole. Thinking about van Manen's (1990) lived space it felt like there were no limits on the space around them. They were part of an enormous plan and their individual lives paled into insignificance compared to this. Their spatiality of the situation (Merleau-Ponty, 1962) was limitless and unknown.

There is nothing else
I happen to just be in the universe as a dot
And part of the whole and that's good enough
It has to be good enough I can't imagine anything else
Kate

For John meditating on the bigger picture was looking at the processes of nature. He found his experience of looking at natural phenomena, such as volcanoes, reinforced his belief that he is an insignificant part of the picture. Similarly Chao et al. (2002) found that a major factor in "spirituality" is marvelling at the beauty of the world.

I went to a place right in the South of Japan
And there is a volcano there
It was actually billowing
It was sort of more or less alive

And the whole earth
Trembled
It was just an amazing thing
The power of it was just immense
And you realise what an insignificant little bunch we are.
John

Given that our emotional well-being is associated with how we feel about our bodies (van Deurzen and Arnold-Baker, 2005), the individuals in this mode of being felt relaxed since they had stopped placing as much emphasis on the physical dimension. Because their bodies were not working as they had done before the cancer, they

observed with physical world from afar rather than trying to participate. The individuals in the transcendent mode of being felt happy and calm as they thought about the way that life works and how they fit into the larger process. There was less emphasis on their individual contribution to the physical world and so instead of trying to control their environment, they were letting themselves be looked after by the whole.

How do I live my life whilst thinking like this?
I just completely relax
As I say I enjoy it
And that to me is everything

So I don't even think about it
It just goes round and round and round
And it's beautiful
John

Participants in this mode of being did not have any interest in material goods and instead expressed a need for a "simple" life. Being-with-others in a physical sense was about sharing an experience rather than interacting with the material world.

I've had some of the most poignant and best presents
And best lovely sit down and eat with the poorest of people
And there's this wonderful kind of sharing with what we had
And that is I think another joy
Hatty

In the transcendent mode of being, participants were very aware of their being-towards-death. Individuals considered death as the final end to the physical world. However, death was not viewed as dichotomous but rather on a continuum.   Over the course of their illness they would find themselves on another plateau closer towards death. John and Kate found themselves almost experiencing death but then waking up again.   Yalom (1980) suggested that life and death are interdependent; they exist

simultaneously not consecutively. This was true for participants in this mode of being whose daily lives were accompanied by death.

Sometimes five days at a time I become withdrawn and sleep
Then my body comes back together again
And I think "no don't do this,
I was quite happy where I was, don't come back again, I've got to do this again now"

Then I plateau off at another level
Kate

Participants in this mode of being had clearly though a lot about what death may be like. The moment of death was viewed as something peaceful, an extension of a process that is already happening. They spoke of drifting off in their sleep, which was another part of the natural process. John and Kate spoke about images of the mind separating from the body and floating away. Thus embodiment for these participants was about life, and death was the lack of body.

One of the things she [his mother] *said was your spirit is connected by a silver chain*
And it will float above your body
And then when you wake up it will just come back into you
If it breaks then you've gone
You've just passed on
John

Death was not something to be feared in this mode of being. The participants commented that they were content with the idea of dying when the time was right. On the contrary life was seen as the hard part. As the participants spoke during the interviews I also found myself relaxing about the idea of death and when trying to step into their world I felt an overall sense of calm. Individuals in this mode of being reflected that death had been present in their lives since childhood. All of the individuals discussed memories of their parents talking about death and therefore being-towards-death was not a new concept for them. This added support to Yalom

(1980) suggestion that concerns about death and our modes of dealing with it are deeply rooted in our past.

Once you're born
You die
Eventually
So that part I'm not scared of

My parents taught me
Because my dad always said, he used to work in a hospital
So he always said that everyone is going to die and there is nothing to be scared of
Edith

For individuals in the transcendent mode of being, interacting with the day-to-day physical world was not as meaningful as those in the everyday mode of being. Viewing themselves as part of a whole, and understanding how they fit into the bigger picture was important to their experience of "spirituality" and helping them create meaning. They had chosen not to continue with treatment, and did not try to relate to their physical bodies. Instead they meditated on the pattern of the universe and thought about how their lives were only a tiny part of the whole. Consequently the individuals felt relaxed and calm, and welcomed death as the end of their struggle with the physical dimension. Individuals in this mode of being had learnt about death from an early age and so this stage of their life was not a shock.

3.3.2 Social Dimension

In terms of being-with-others in the social dimension, or *Mitwelt* (Binswanger, 1963), individuals looking at life from the transcendent mode of being began to withdraw from people in the physical world. They maintained a few key relationships but there was a sense of withdrawing from their community and focusing on their inner world. Thus there was not much emphasis on van Manen's (1990) existential of lived human relation, since meaning was not generally found in relation to others-in-the-world. This made sense for how they were feeling about life, and to live any other way

would not be helpful since they were not able to interact in the physical, and therefore social, dimension as they used to before the cancer.

I need to not become involved
Just stay happy in the other world, in my world where I want to be in
I feel that I can let go
There's nothing stopping me
Not people demanding
Kate

Individuals in the transcendent mode of being felt other people who did not understand their way of being-in-the-world interrupted their peace. Thus as their worldview changed, so did their interrelatedness with other people. They felt people who are "well" have a completely different worldview to those in the transcendent mode of being. The "well" people tried to impose their ideals of how to manage cancer onto the individuals in the transcendent mode of being which they felt was a consequence of the "well" person's death anxiety. As a consequence they felt annoyed and frustrated at having "well" people interrupt their peace with their own needs. They felt that these people did not try to understand their worldview. In response, individuals in the transcendent mode of being withdrew from unhelpful relationships either by ignoring them or placating them to save their energy. Willig (2009) found a similar experience during her own reflections on having a diagnosis of cancer. One of the types of discourse she found when people discussed her health was "this is not and does not have to be". Her friends tried to suggest solutions such as private medicine and diets which although was said with good intentions, served to negate the possibility that making peace with death was an option. Willig (2009) found other people's narratives unsettled her own meaning and threw her back into a state of confusion and anxiety. She used her own reflections, therapy and the support of her partner to create and hold on to her meaning.

The only distress is when people are trying to
At this late stage trying to
With their fear
Convert me

That's one issue

So I'm letting go
I'm not even going to reply to that
I'm not interested in wasting my energy
They're interested in their needs for my, not sure what, they're peace really

It's extraordinary
Kate

In this mode of being, participants felt that the doctors and other people at the hospice understood their way of being-in-the-world because they were either in the same situation or had a lot of experience in this field. Thus people in the hospice were aware and accepting of their own being-towards-death and did not try to project their own denial on to the person with cancer. Consequently they felt that these relationships were genuine and understanding since the other person would try and understand life from their worldview. Kate described her doctor's comments as "magical", suggesting that it was highly unusual to be completely understood. It was within these relationships that they were viewed as people, rather than a person with cancer.

This hospice has been fabulous
They've held me when I've been sad
It's that sort of thing which is love and is most important

And they accept me as I am
They don't treat me like some half-wit
Which I don't think I am
They treat me as an intelligent human being
Hatty

Having experience of death and thus being aware of one's own mortality was important for connecting with people in the transcendent mode of being. Kate felt her

partner understood because of her experience of death.   The following extract was directed at her partner:

You're [her partner] *very much involved in death*
You've done ten years
Your experiences in life have been very influenced by death

I don't think it would have happened if you hadn't been the person you are
You wouldn't have taken on
You wouldn't have helped getting me through
With all the support on the journey
Kate

The individuals need to interact with someone who was 'attuned to death' was apparent during our interaction in the interviews.   I was very aware of my own age and healthy status during these interviews and wondered how they may feel about my understanding.   I felt that using the phenomenological approach helped me to try to understand their worldview but I could not completely dissociate from my own 'thrownness'.   Both Hatty and John commented that I might not understand what they were saying since presumably I am not operating in a transcendent mode of being.

Its that cyclical thing

I don't think it is complex
I'm sure if you keep thinking about it then you won't either
However you like to think about it
that to me is just right
John

Family was still important to individuals in this mode of being, even though their being-in-the-world may be very different.   They were detaching from their family and making sure they were prepared to carry on life without them.   However affirming their love and discussing how they were viewing the world was still meaningful to these individuals.   Chao et al. (2002) also found that communion with

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others was important in the "spiritual" experience of Taiwanese women. Similar to participants in the transcendent mode of being, this communion involved having a caring relationship with others, but without over-attachment. For example, one woman described being able to let her children go and giving them their own destiny which was mirrored in Kate and Edith's interview.

I think they [the children] *find it, they still find it very difficult*
But they've had a long time to deal with it
But they're in the well world and they've got their dreams for their future
And my dreams are somewhere else
Kate

As with the everyday mode of being, the social dimension was very much tied into the physical dimension. The participants' greatest fear was being a burden to other people as a result of their physical limitations. It was important for these individuals to maintain their independence and to only interact with other people in a social dimension rather than having someone help them. All individuals in transcendent mode of being commented that they would rather die than become overly dependent on others. Quality of life was more important to them than longevity, especially since death was not something to be feared.

I don't really want to be dependent on people
I don't want that at all
I've always been very independent
I'm not looking forward to that side of it if I have to go down that road

I wouldn't like to prolong it if you know what I'm saying
If the time comes where I can't look after myself
Then just let nature take its course
Edith

The participants' experience of "spirituality" and meaning-making in the social dimension was associated with their transcendent view of the physical world. They detached from relationships that were not conducive to their worldview to avoid

interrupting their peace and quiet. Connecting with people at the hospice and those who understood their worldview was still key to their experience of "spirituality" but these relationships were few and far between. They found meaning from their relationships with their family, but there was a need not to over-attach in order to prepare them for their death. An important source of meaning and "spirituality" was maintaining their independence to continue in their current mode of being.

3.3.4 Personal Dimension

Individuals in the transcendent mode of being had a well defined *Eigenwelt* (Binswanger, 1963), or personal dimension that was not associated with the social dimension. Their vehicle for being-in-the-world was not functioning, and so they retreated into their minds since the physical dimension did not hold as much meaning anymore. Our inner world is experienced as mineness (Heidegger, 1927; 1962), and there was a sense that they were all very sure of their sense of self independent of the physical and social world. The experience of the self is a process of becoming and transforming (van Deurzen and Arnold-Baker, 2005). The individuals' 'self' had gone through many changes over the experience of their cancer, and their sense of self become more fluid as they progressed towards death. Standing on their own had been difficult but it was now a comfortable place. The capacity to transcend the immediate situation presupposes *Eigenwelt* (May, 1983). Transcendence is an inseparable part of self-awareness since being aware of oneself implies the ability to look objectively at oneself in a situation and consider the possibilities of freedom. Individuals in the transcendent mode of being were able to stand outside of their situation and make choices about how to be-in-the-world. Individuals regarded retreating into their inner world as a choice, rather than forced upon them, demonstrating that transcendence in *Eigenwelt* leads to freedom (May, 1983). Chiu et al. (2000) also found that this was an important facet of "spirituality" for Taiwanese women with breast cancer. Transcendence involved liberation from the world and the opening to life and death which was also true of these participants in the current research.

What is life like at the moment?
Peaceful and quiet
Well I attempt to make it as peaceful and quiet
And withdrawing really from the well world

I sort of divide into the well world and the ill world
Where I am
And I don't want to be in the well world
There are just so many demands I am not really interested in anymore

I want to be in this side
Kate

Although individuals in the transcendent mode of being all admitted to sometimes feeling sad or angry, they felt quite accepting of these emotions. Their state was reflective of their internal processes and they were not concerned by any changes. Part of authentic living is being aware of our moods (Cooper, 2005). For Sartre (1943) emotions represent the link between our worldview and the situation. By becoming more aware of our emotions we can be more self aware of the interactions between the self and the world (Heidegger, 1927; 1962). Therefore for individuals in this mode of being, becoming aware of their emotions aided them to experience freedom and choice and continue their fundamental bond with the world. Chao et al. (2002) found similar results with Taiwanese patients who were terminally ill. The participants found the communion with the self component of "spirituality" was discovering the authentic self and embracing wholeness. Likewise, individuals in the transcendent mode of being accepted their whole self.

I also am not ashamed of any emotions
I might even just start crying now
Don't worry about it
It's just one of those things that happens
John

Participants in the transcendent mode of being identified the personal dimension, and in particular transcendence, as a fundamental part of their experience of "spirituality" and meaning-making. Their sense of self became more fluid as they detached from the physical and social dimensions and they were able to transcend the situation and

review their freedom. Consequently they embraced their whole self and became accepting of their emotions.

3.3.5 Spiritual Dimension

van Deurzen (2002) proposed that the spiritual dimension can involve a relationship with the unknown or metaphysical level of existence. Individuals found meaning in the spiritual dimension by considering their 'thrownness' in the context of the whole. Yalom's (1980) concept of cosmic meaning, where people create meaning from the overall pattern of the universe, was similar to this mode of being, although participants were not describing this with reference to a higher being. Uncertainty and not understanding the ultimate meaning in life was a core concept in McGrath's (2004) findings of "secular spirituality". Likewise these participants felt there was an overall pattern but they were not anxious about finding all the answers. Their relationship with the whole had been evolving over time and was something they were making sense of as time progressed.

You know that fact that we're all
We're all one really
As far as I'm concerned
We're all one

We go off
You can call it what you like
Any name is the same
Heaven or whatever

Then the next time there is a rainfall
We'll all come down in the rain
Feed the soil
And the whole process is completely cyclical
It just never never stops

And that for me is just what it is about

John

The individuals in this mode of being had various methods that helped them connect with the whole and find meaning in the overall pattern of the universe. Music was important for both Kate and Hatty as it allowed them to get in touch with their emotions. Music has historically been considered a powerful medium for realising thoughts and emotions (Grey, 1994). Chao et al. (2002) also found that communion with nature was achieved through complementary therapies such as music.

To me music is religious
Not religious
I mean it is it makes you laugh, it makes you cry
It makes you want to dance
Hatty

Grey (1994) commented that when time is limited it can be important to employ imaginative methods to find meaning. Kate had tried many creative tools to help her find meaning including art, yoga, meditation and reading. She also put together a book of her art work detailing her journey with cancer.

I have ten years of yoga
Meditation
Working
Reading an awful lot of books..

..I mean I think that it's a background of all these books I've read over ten years and
Their entirely appropriate literature

I kind of found my way through
Kate

Edith and Hatty used humour as a tool to becoming more objective and find meaning in their situation. Carson noted (1989) *"humour is transcendent – it momentarily*

removes ones from an isolated personal sate to join in surprise at the ludicrous situations of human beings" (Carson, 1989; p.198). Johnson (2002) found that many individuals with cancer find laughing to be spiritually uplifting. After interviewing nine patients with breast cancer (who were not in the terminal stages), it was found that humour helped the individuals not take things too seriously and develop deeper relationship with staff (Carson, 1989). Hatty felt that laughter helped her lift her spirits and Edith found that joking with her family and her doctor helped her view herself as part of a bigger picture.

I think I got it from my dad.
My sense of humour
It's enabled me to not feel too bad
Some people say no you're not
Its too hard
you're smiling to make us laugh

But I'm smiling because you need that
The doctors say oh no its Edith!
I always have a joke
Edith

All participants in the transcendent mode of being felt that they had enjoyed their life and fulfilled their purpose. There was nothing more to be gained from the everyday world, they had done everything they could given their context in the world. Nothing more was required of them and they were relaxed and able to focus on themselves as they grew closer to death. This provided further evidence for Yalom's (1980) assertion that meaning and purpose are different concepts since they still found meaning in the absence of purpose. The interview demonstrated that these individuals were reflecting on their lives and thinking about the things they had enjoyed. For example John discussed his career in music and Hatty reminisced about her rebellious childhood. Both Edith and Kate reflected on bringing up their children, but felt that now they could let them go.

What is my purpose in life?
That has gone now
Because I have lived my life
I have raised my three children

I thought that I'll probably sat down and talk with them and say I have no regrets
Maybe I might have done some of it differently
I have no regrets
I enjoy my life

Cause while I was working I took time off to go out and have a bit of dance and have
      social life
And I don't know exactly what my purpose in life has been
But certainly I haven't got one now
Edith

Kate in particular felt that there was nothing left to do in the physical world. She was pleased that she had been given more time by having chemotherapy, which allowed her to put everything in order. Thus time and purpose had been relevant during treatment but was not important at this stage of their being-in-the-world.

You know at the beginning of the ten years I didn't know how long I was going to live
at first
Ten years is quite a long time
To have as a gift to get through it all
And I do see it like that, I see it as a gift really
Time to put everything today

And I definitely reached the end of this bit now
It is good enough for me
Kate

Linear time is less relevant to individuals in this mode of being. They have lived their life and are existing in the present moment. Since they no longer felt they had a

purpose, they were living without a particular directional pull towards the future. Thus Heidegger's (1927; 1962) ecstasies of past, present and future, were all experienced at once, which he regarded as authentic living. van Manen's (1990) 'lived time' existential was therefore experienced as a suspension of linear time. They concentrated on being patient and seeing what would happen next. This was reflected in the interviews as the participants were in no rush to finish the conversation. My conversation with Kate lead me to reflect on space and time during the interview. She spoke at a constant pace that felt like a meditative trance. I felt myself that time was standing still.

I don't know when it will be but it doesn't really matter
Time and body is not, I don't need to worry about it anymore
Which is very nice
It's a very nice feeling
Kate

People grow up with a world view which they question over time (van Deurzen, 2002). In viewing the world from afar, individuals in this mode of being began to reflect more about the state of the world as a whole. They started to think about good and evil and prejudices and injustices in the world which is an important facet of the spiritual dimension (van Deurzen and Arnold-Baker, 2005). They spoke passionately against greed and material gain. This was consistent with their view on the whole of humanity, rather than focusing on their individual needs.

And greed
I hate greed
I bought things for people when I had no money
In Oxfam or I made something

And I really thought about that little thing
What they would like something silly
Something always precious
Which hasn't cost much money
Sometimes not a penny

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And its that sort of thing that people seem to have forgotten
Hatty

Hatty and Edith expressed a hope that the world would change even though they were no longer going to be a part of it anymore. Edith wanted the world to be good for her children. She was worried about the future for humanity rather than herself.

I hope that they will give him [Barack Obama] *time to make this world a better place*
For my children and grandchildren
I do hope that
And that is one of my fears

I do hope they give him some time to stop all this war
And killing all the people's children and all that
I can't see sense in that
Edith

van Deurzen and Arnold-Baker (2005) argued that we have become used to relativising our thinking about good and evil in an effort to be less judgemental. They suggested that authentic living should involve judging each situation on its own merits rather than conforming to political norms. Hatty's interview was very political and she expressed her concerns about having too many people in the world and the impact this may have in the future. During the interview I felt uncomfortable listening to her argument as it seemed to cross the boundaries of political correctness. However on analysis it seems that she was not trying to be derogatory but instead trying to relay her own considered moral values that might be perceived as going against popular opinion. Thus her political stance demonstrated her evolving sense of self that was not reliant on other people. Hatty's interview became focused on her motivation to encourage people to take responsibility for deciding what is right and wrong rather than just accepting society as it is.

And it's amazing
Terrifying as well

I mean what's happening now and the greed
What we've all got is there is too many people in the world

The Catholic church should pull its socks up and see exactly what we're all doing
Too many people and they're condemning generations after us to hell
Hatty

As well as emphasising the need for personal moral values, all participants in this mode of being emphasised the need for their own personal beliefs about religion. Even though John and Edith considered themselves Christian, they did not want to be labelled as such. Both used Christian terminology such as "heaven", "praying" and "limbo", but both emphasised the need for their own religion. Hatty and Kate acknowledged the influence of Buddhism on their beliefs and values, but did not necessarily want to be labelled as "Buddhist". Instead they felt more comfortable describing their own philosophy. Again this is consistent with the idea of being an individual and independent self.

Am I religious?
Yes and no
'Cause there are some things I do believe
And there are some things that I think well how can you believe that?

... I use my brain
Who is right or wrong?
I don't know
But I use my brain because no one should tell me a bucket is a spade
Edith

As a result of viewing the world from afar, both John and Hatty felt that differences in religion were no longer visible. They felt all humans are the same as they thought about the pattern of the whole world.

I don't care whether one's Muslim
Any religion at all

We all end up in the same place…

…You know that fact that we're all
We're all one really
As far as I'm concerned
We're all one
John

Although some authors suggest that spiritual issues may become more prominent as individuals approach death (e.g. Thomas and Retsas, 1999), the individuals in the transcendent mode of being claimed their beliefs had not changed significantly over their life. As life had always been accompanied by death, their way of thinking about the meaning of the world had not changed dramatically, although it had evolved. Edith suggested that although her beliefs had not changed, they were more in the forefront of her mind because people kept reminding her of her illness.

Do I think about this more in recent times?
No that was always me
It's only because people know that I am not well that they bring it up
It's probably more in my thoughts now
Because every time they bring this sort of thing up its comes in my mind
Edith

In the transcendent mode of being an important part of the experience of "spirituality" was therefore finding meaning from thinking about the whole of the world or universe. This was aided by listening to music, creating artwork or reading literature. Although they maintained meaning in their life, the participants felt that they had fulfilled their purpose and had nothing left to do. Thus they were living in the present moment and not driven towards a goal in the future other than death itself. Having individual beliefs was important for their experience of "spirituality" and meaning-making, in terms of politics and religion. Although they felt that making judgements was a personal exercise, their thoughts about the state of the world reflected their reduced need for individual meaning and instead increased their desire to think about collective meaning.

3.3.6 Summary

Relating this back to Spinelli's (2007) proposition that people impose a 'worldview' structure on the interrelated 'worlding', participants in the transcendent mode of being had an expanding and flexible worldview.   Their perspective on the world had less sedimentations (Spinelli, 2007) given that there were less boundaries between the self, world and other, leading to the individuals seeing themselves as part of the constantly changing worlding. The individuals incorporated their experience of cancer into their experience of the ever-changing worlding and attempted to make sense of life by seeing themselves as part of a larger structure. By viewing themselves as part of an interrelational structure they found new ways of being-in-the-world as their cancer progressed, which had less emphasis on the physical and social domains. Consequently the individuals continued to feel that they were free to make choices. Spinelli (2007) suggests that the more open the worldview, and thus the more it represents worlding, the less the person finds stable meaning.   However, the participants in the transcendent mode of being still found their worldview meaningful suggesting that they have the necessary sedimentations in place to avoid feeling overwhelmed by the chaotic, meaningless worlding.

As with the everyday mode of being, the experience of "spirituality" and meaning-making for participants in the transcendent mode of being can be described with reference to all of van Deurzen's (2002) dimensions of human experience. Individuals discussed their experience of "spirituality" as related to withdrawing from the everyday physical world. The physical dimension in the transcendent mode of being was related to the world or universe as a whole. Consequently their own physical presence was insignificant when viewed in this context. The individuals continued to find meaning and experience "spirituality" with certain people in the social dimension. Other people who were ill, or people who had experience of interacting with those who are dying, were considered important connections. Interactions with their family added to their experience of "spirituality", but it was important for these relationships to not feel over-attached in order to let go.

The personal dimension was a fundamental aspect to the experience of "spirituality" and meaning-making in the transcendent mode of being. As they found less meaning in the physical and social domains they experienced "spirituality" and meaning within the self and inner world. With less emphasis on time and space, the individuals in the transcendent mode of being experienced more freedom and felt at peace. Death was therefore viewed as liberation from the physical realm and was not something to be feared. In order to facilitate their experience of "spirituality" or meaning-making, participants in the transcendent mode of being found it helpful to listen to music or engage in art. Also in the spiritual dimension was the importance of having political and religious beliefs that reflected their individuality rather than conforming to social norms. Also, their opinions and beliefs were derived from considering the whole of humanity or the world rather than thinking about concrete examples from their life. Overall the described experience of "spirituality" seemed to closely resemble the Chao et al. (2002) and Chiu et al. (2000) studies on the Taiwanese population. The Eastern cultures are less individualistic which was a theme reflected in the transcendent mode of being.

Only John explicitly said that the phenomenon he was describing was "spirituality";

I think this is spirituality
I think it's all connected.
But as I say it in no way effects the cyclical cycle of the planet.
We're just purely pawns in that.
John

Kate felt that the "spiritual side" was beyond the physical and mental;

It was my doctor actually
She said well we've finished with the physical side, now what about the mental side
And spiritual side
Which is unusual for a doctor
Kate

She also said that "spirituality" can be confronted by music;

Music for me is absolutely essential

To listen to it all

You can confront spirituality through music

Kate

Edith described the phenomenon in terms of "faith" and Hatty did not ascribe a particular word to what she was discussing. Nevertheless, having explained to the participants that I was trying to find out about their experience of "spirituality" or whatever words they wanted to use, all the individuals in this mode of being seemed to know what I was referring to and did not need much prompting to discuss their experience at length. Therefore I feel that the term "spirituality" is still relevant to individuals in the transcendent mode of being.

3.4 Context Influencing the Mode of Being

Central to existential theory is Heidegger's (1927; 1962) observation that humans are thrown into a certain set of circumstances, such as time, culture, gender and so on. Within these circumstances we must make choices, take responsibility and find meaning in our world. From analysing the experience of "spirituality" in the current study there seemed to be some situations that facilitated individuals into the "everyday mode of being" or "transcendent mode of being". The circumstances identified were treatment history, family and relationships and the experience of death throughout life. Also, since the modes of being are not mutually exclusive, there were times when the individuals moved between the two.

3.4.1 Treatment history

McGrath (2004) found individuals with haematological malignancies could not make sense of their experience until they had finished their aggressive treatment. They described focusing their energy on surviving the treatment rather than making meaning and reflecting on "spirituality". In the current study all individuals in the everyday mode of being were all undergoing treatment. They also described being

overwhelmed with doctors' appointments and treatment options and struggled to complete their day-to-day activities. As their cancer progressed different treatments such as chemotherapy and major operations were suggested and they did not know what to expect from in the future. Therefore it was probably more difficult to find time to explore their sense of self and think about themselves in the context of the whole.

The trouble is it's all too much
Because I'm going from one operation to another
I was going to get a job at the local school down the way
I thought I had plans for October
Jane

On the contrary, individuals in the transcendent mode of being were not receiving anymore treatment other than pain relief either by choice or because they had exhausted all the options. Therefore they were not dependent on the doctors and there were no unexpected medical decisions around the corner. They were in control of their treatment decisions and were concentrating on other areas of well-being such as eating organically, meditating and music. Thus individuals in this situation were able to find time to reflect on what had happened and making sense of their being-towards-death.

3.4.2 Family and relationships

Kate commented that you need the help of the family to be able to detach and view the world from afar. This was supported by Sandra (the only participant with a dependent child) who commented that she had no choice but to stay alive for her children and keep going with her day to day tasks. Similarly Jane was facing a crisis after her husband had died and was sorting out moving house and financial issues with her step-daughters. Thus her day-to-day living was consumed with resolving problems which did not allow her for much reflection time. Without any demands from anyone else the person is able to gain more solitude and withdraw from the physical and social dimensions thus gaining a more transcendent perspective. Those

who did have people dependent on them or were facing crisis had to focus on everyday living.

What is important to me?
My kids
That's the main thing
That's the most important thing

I have to think about how it's going to affect them this life
I can't die now
my son's got his GCSE's
I don't want it to affect him

I haven't got a choice, I can't
Their my kids!
To be hospitalised I haven't got a choice
So nothing I can do about it, just live
Sandra

Further to this observation is the finding that individuals in the everyday mode of being did not have a partner. Therefore perhaps not having a close supportive relationship meant that they could not pass everyday responsibilities onto another keeping them grounded in the everyday mode of being.

I need to not become involved
Just stay happy in the other world, in my world where I want to be in
I feel that I can let go
There's nothing stopping me
Not people demanding

And you [her partner] *unfortunately have to pick up a lot of the stress that these*
friends put on
To get them to back off
Kate

3.4.3 Experience of death throughout life

People in the transcendent mode of being commented that they had known about death from life, this had been something present in their life always. In contrast, the individuals in the everyday mode of being seemed to be more shocked by facing their mortality, and did not comment about any conversations in the past about death. Therefore perhaps being aware of this from an early age facilitated the transcendent mode of being.

I expect I've always thought of death and the fragility of the line
Which is very precarious really

And if you live in a country where life is precarious
Like Zambia or South Africa or Mexico
I'm sure it must change your attitude towards presuming life is yours
So I think that's happened since I was very small..

... I've always respected the two sides
Kate

3.4.4 Moving between the two modes of being

The two modes of being were not mutually exclusive and there were instances in the interview when the participants described moving between the two. This was particularly the case for individuals in the transcendent mode of being. Although they spent most of the time withdrawing from their body into an inner realm, there were circumstances when they interacted with the day-to-day world and found meaning. For example Kate and John derived pleasure from eating, and all participants acknowledged the time they enjoyed with their friends and family. Therefore the different modes of being exist *within* the individual, and participants could find meaning and experiences of "spirituality" in both circumstances.

Anyway, they go up to Hampstead,

Lovely church, Georgian

It's beautiful

Singing carols on Christmas Eve

He said "would you like to come Grandma"

And I said "I would like to come Edward

But I can't walk very much now"

He said "I'll hold your hand"

And I said "that would be good"

And of course you can't talk cause you'll cry!

It's those things that are so precious

Hatty

3.4.5 Similarities with Maslow's (1968) Hierarchy of Needs

Spinelli (1989) noted that the existential concept of living authentically bore a striking resemblance to Maslow's (1968) hierarchy of needs. Maslow (1968) proposed that individuals have a set of needs that are predetermined in order of importance. His theory is often depicted as a pyramid consisting of the five levels of need; physiological needs; safety needs; needs of love, belonging and affection; needs for esteem; and needs for self actualisation. The first three needs represent deficiency needs, which when fulfilled can allow the person to seek personal growth needs through self-esteem and self-actualisation. If a lower set of needs is no longer being met, the individual will temporarily re-prioritise their needs to focus on the lower levels.

Spinelli (1989) argued that there are no end points to authenticity or self-actualisation and that both models focus on the here and now rather than on future rewards. Expanding on these similarities, it seemed that participants in the everyday mode of being needed to focus on their physiological needs and sense of belonging which prevented them from transcending their situation and experiencing the freedom of authentic living. Their experience of "spirituality" was therefore about belonging to the physical and social world. In contrast, individuals in the transcendent mode of

being had their lower needs fulfilled having stopped treatment and feeling secure in their relationships, and therefore were able to explore their inner sense of self. Consequently they experienced "spirituality" more in terms of the interrelated worlding which leads to authenticity (Spinelli, 2007). However this may again imply that the transcendent mode of being is a more developed of better position, which is not the intention of this analysis. Instead it is useful to consider the context within which people interact with their environment and how peoples "throwness" may influence their priorities.

4. CONCLUSION

4.1 "Spirituality" and Meaning-Making in Advanced Cancer

4.1.1 The role of meaning-making when facing advanced cancer

From the analysis it is clear that finding meaning is extremely important for people with advanced cancer. Although the different modes of being lead to different types of meaning, all participants spoke of what was important in their lives and how they made sense of their illness. For participants in the everyday mode of being, meaning was found in everyday tasks. Thus the findings demonstrate the importance of understanding the meaning of what could be considered normal routine tasks for individuals in this mode of being. For participants in the transcendent mode of being, meaning was found in viewing themselves as a part of a bigger picture. For individuals viewing the world in this way, it was important to explore how they felt their life fitted into a bigger plan. For each individual the whole or pattern they belonged to was unique, highlighting the importance of exploring the individual meaning and the tools they use to help meditate on significance of their lives.

4.1.2 Application of the Term "Spirituality"

Previous research has applied the concept of "spirituality" to all people regardless of whether or not they explicitly use this word (e.g. Watts, 2009). The health authorities assume everyone has a spiritual dimension (e.g. Royal College of Nursing, 1993), but there is no evidence that the patients themselves agree with the assumption. Salander (2006) argues that "spirituality" is a term that has been substituted for existential meaning. He questioned the validity of such a diffuse concept given that "spirituality" lacks any systematic meaning and asks what is the advantage of this label? Salander (2006) proposes that because existentialism has denied God in the past (e.g. Nietzsche, 1885; 1961) authors are wary of imposing existential terminology onto individuals who may not deny the existence of God. According to Salander (2006), using words such as "why", "meaning" and "purpose" are existential

questions we raise when we are exposed to the existential givens of life (e.g. freedom, isolation, meaninglessness and death; Yalom, 1980). Thus Salander (2006) claims that using spiritual discourse on these existential concepts only serves to confuse rather than aid understanding. Consequently he suggests that "spirituality" must be restricted to a definition of a worldview, or ontological position, in contrast to a religious and a secular worldview. Thus a "spiritual" worldview according to Salander (2006) should be a different way of looking at reality compared to those with a religious or secular world view. Spiritual needs are therefore only relevant to those with a "spiritual" worldview.

The current research has shown that not all people connect with the term "spirituality". It would therefore seem counterintuitive to continue enforcing a term that does not aid conversation and perhaps even hinders the ability to connect with a person. In agreement with Salander (2006), I propose that "spirituality" is referring to a worldview, and in this case, the transcendent mode of being, although there could be other spiritual modes of being since this research is not exhaustive. Conversely the everyday mode of being is in line with a secular worldview, which in this case is belonging-in-the-world. All modes of being in the world are available within human beings. Therefore every person has the potential to adopt a spiritual worldview. However, if the person is not viewing life from this ontological position, it is not helpful to impose spiritual terminology onto the individual. In agreement with Walter (2002), it seems that to continue to do this is poor social science. Furthermore, it is highly likely if we only used the term "spiritual" for those who have adopted a "spiritual" worldview, we would be left with a more meaningful and cohesive concept. Therefore van Deurzen's (2002) fourth spiritual dimension is misleading as it implies that "spirituality" is something separate from the physical, social and personal domains and a dimension that is relevant for everyone. Perhaps it would be less confusing to revert back to van Deurzen-Smith's (1988) original label of *Uberwelt* and refer to it as the ideal dimension.

Although participants in the everyday mode of being were not referring to "spirituality" they were still discussing an important phenomenon which should not be ignored. Their discourse was more closely associated with the existential search for meaning without using spiritual terminology. More specifically it seemed that

individuals in this mode of being were trying to find meaning through their worldview in the physical and social domains. I propose the term "belonging-in-the-world" since these individuals were trying to negotiate how they still belonged in the interrelational world both physically and socially. For these individuals the ultimate meaning or purpose in the world was not relevant and instead they were attempting to find meaning in day-to-day activities. This relates to Yalom's (1980) term "terrestrial meaning" where people attempt to find meaning entirely in the secular world.

There were both religious and non-religious participants in both modes of being, suggesting that "spirituality" was a distinct concept from religion. This provides further proof that the terms "religion" and "spirituality" should not be used interchangeably. However I did not interview anyone who strongly affiliated themselves with a particular religion but perhaps there is a "religious" worldview for individuals who adhere to the practices and beliefs of an organised religion. This could be explored in further research in the area.

4.1.3 Transcendence vs. Transformation

Frankl (1962) proposed that meaning is derived from creating work or doing a deed, experiencing something within the world such as goodness or love, or in one's attitude towards an unavoidable situation. Participants in the everyday mode of being found meaning in the first two categories by doing something for someone else or experiencing something within the world. In contrast the people in the transcendent mode of being found meaning in the latter category; by changing their attitude to the situation. Reker (2000) suggested that new ways of being-in-the-world are achieved through two processes: transcendence and transformation. Transcendence involves making meaning by rising above one's circumstance. Transformation is the process of transforming is giving a reality a new potential. Frankl (1962) argued that changing one's attitude to an event involves transcending the situation and reaching beyond the self to find meaning. Thus participants in the everyday mode of being were attempting to find meaning by transforming their situation, whereas in the transcendent mode of being, individuals found meaning by transcending their situation.

Living with a diagnosis of cancer sharpened the focus of the individual's worldviews, but the two possible modes of being were very different. Existentialism is concerned with how we relate to the "other", which can be either the individual or the group. The main difference that emerged from the two modes of being was that the everyday mode of being was concerned with the microcosm (i.e. individual activity) whereas the transcendent mode of being was concerned with macrocosm (i.e. greater universe). The participants in the transcendent mode of being experienced spirituality by transcending their situation through a macrocosmic worldview. In contrast individuals in the everyday mode of being experienced belonging-in-the-world by transforming new meanings within the world via a microcosmic worldview. Thus spirituality or belonging-in-the-world was a product of the "I-thou" experience where the "thou" was either humanity/the universe or persons/environment. The everyday mode of being resonates more with the Western individualism, correlating with studies such as Watts' (2009) UK ethnographic research. In contrast the transcendent mode of being more closely resembles Eastern collectivism, and their experience of "spirituality" linked in with studies such as Chiu et al. (2000) and Chao et al. (2002) on the Taiwanese population.

Transforming or transcending the situation had important implications for the way the person experiences van Manen's (1990) existentials of existence. In the everyday mode of being, individual's primary meaning was found in lived human relations and individuals focused on enhancing the positive relationships in their lives. In contrast in the transcendent mode of being, individuals withdrew from lived human relations and turned towards their inner self to find meaning. In terms of lived body, the everyday mode of being continued to struggle in the physical world whilst enduring further treatment, whereas individuals in the transcendent mode of being attempted to dissociate from their body and decided not to continue with any further treatment. The transcendent mode of being had a limitless and immediate sense of lived time, whereas the everyday mode of being was still focusing on linear time in relations to goals and purpose. Finally, in terms of lived space individuals in the everyday mode of being have a small and immediate lived spatiality whereas the transcendent mode of being has limitless space within which they are a tiny part of the larger picture.

Spirituality has often been conceptualised in the literature as a journey (Chui et al., 2004). This was echoed in the findings of McGrath (2004), Thomas and Retsas (1999) and Chiu et al.'s (2000) qualitative studies. All of these authors describe "spirituality" as the process of being diagnosed with cancer, learning how to face the reality of their limitations and once this was achieved the individuals made sense out of what had happened to them by thinking about the bigger picture of their lives, the world or God. Thomas and Retsas (1999) and Chiu et al. (2000) both considered the final stage of meaning-making as a process of transcendence. For Thomas and Retsas (1999) the final stage of "putting it all together" consisted of transcendence, becoming "spiritual" and expanding consciousness (although these terms are not explored in detail). They described participants looking at their lives as a whole, discovering their 'self' and shunning materialism, similar to participants in the transcendent mode of being. Chiu et al. (2000) described the final stage of transcendence as connecting with the self, others or God. They found transcendence allowed "spirituality" to evolve to higher order wholes and connectedness, which left them feeling liberated with the world, open to life and death and experiencing the present moment. Again, this echoes the experience of people in the transcendent mode of being.

Despite participants referring to the process of transcendence as "being spiritual", both Thomas and Retsas (1999) and Chiu et al. (2000) concluded that the entire journey of the participants starting from diagnosis was "spiritual". However, considering the findings of this study, I propose that it is this stage of transcendence that resonates with the term "spirituality" which is supported by the use of this word in participants in both studies. Neither of the studies reported the use of the word "spiritual" in reference of any other part of their journey. However, restricting the use of the term "spiritual" is not to say that there are not important sources of meaning in other parts of the participants' 'journey', and belonging-in-the-world may have been relevant to these participants before they adopted a transcendent worldview. However, I believe that enforcing the term "spirituality" onto every aspect of a person's life is making the concept confused, vague and ultimately meaningless.

4.1.4 Authentic vs. Inauthentic?

As discussed prior to discussing the two modes of being, there was a tension throughout the analysis of considering the transcendent mode of being as "better" or more advanced than the everyday mode of being. Heidegger (1927; 1962) spoke about authentic living as being aware of our individuality, recognising our freedom and taking responsibility for our choices. Therefore it could be concluded that individuals in the transcendent mode of being were living "authentically", whereas individuals in the everyday mode of being were living "inauthentically" because they viewed themselves as having less freedom and a less defined sense of self. However, I have avoided categorising participants into these labels as I feel that it would impose a judgement on the individual's mode of being, which was not the purpose of the study. Furthermore, these terms seem particularly inappropriate given the finding that certain contexts had an influence on how individuals viewed their world and found meaning. Therefore, I maintain that it is useful to consider the two modes of being as different ways of viewing the world rather than providing an example of how to live or how not to live.

4.2 Significance for Counselling Psychology

4.2.1 Approaching a difficult area

Although there has been a 600% increase in research on spirituality in recent years, the current study has shown that this is an extremely difficult area to research. Choosing the right words to recruit participants, conduct the interview and define terms from the data was extremely challenging. Furthermore, asking participants to express an area of experience that lacks a common discourse seemed at times to be impossible. Nevertheless, having persisted with the research it has been shown that there is an important phenomenon beyond general well-being that should be considered when working with individuals with advanced cancer. However, many therapists struggle to incorporate notions such as spirituality into therapy (Milton and Legg, 2000), perhaps because they are unsure of what words to use and how to conceptualise such an undefined area of human experience.

The experience of spirituality or belonging-to-the-world was a fundamental part of meaning-making for the participants interviewed. Therefore exploring these issues seems very appropriate for individuals attending therapy at the end of life. However, the study has shown that it is important to think about the terminology used in therapy to avoid confusion and help the therapist explore the client's worldview. Willig (2009) noted that when people used a different discourse to assign meaning to her experience of cancer, this threw her off course from her own truth, leaving her feeling anxious and confused. She concluded that having her thoughts and feelings validated from a trusted source, such as a therapist, helped her create and maintain her own meaning. Given the findings from this study it is probable that using language that matches the person's experience as well as being accepting and trustworthy is likely to aid the therapeutic process and relationship.

4.2.2 Not a quantitative "thing"

The findings have shown that to explore the experience of spirituality or belonging-in-the-world requires consideration of how the individual interacts with the physical, social, personal and spiritual/ideal dimensions. According to May (1983) existentialism is *"the endeavour to understand man by cutting below the cleavage between subject and object which has bedevilled Western thought and science shortly after the Renaissance"* (May, 1983; p. 49). Ironically, in the context of the current study, this cleavage is what Binswanger (1963) calls *"the cancer of all psychology up to now"* (May, 1983; p 49). Analysis of the individual's interviews adds weight to the existential rejection of Cartesian subject-object duality and suggests that the experience of both spirituality and belonging-in-the-world cannot be considered in isolation from the individual since they are a product of the person's interrelatedness with worlding.

By considering spirituality/belonging-in-the-world as an intersubjective concept, this calls into question the validity of assessing "spirituality" using questionnaires. In support of Sulmasy (2006) the analysis has shown that questionnaires would not be able to capture the intricacies of the I-thou experience which is unique for every individual. Furthermore, spirituality or belonging-in-the-world has been shown not to be a cognitive process but rather an experience of being-in-the-world. Thus

relating the study back to Park and Folkman's (1997) model of coping would also miss the point since spirituality/belonging-in-the-world is not something you *do* but something that is experienced. The quality of description that was gained from using this approach could not have been achieved using a questionnaire and therefore vital points may have been missed if a quantitative approach had been used. Therefore it is advised that Counselling Psychologists should assess spirituality/belonging-in-the-world through a guided conversation rather than through a questionnaire. This approach allows a more meaningful discussion about what this concept means to the individual within their own unique context. Furthermore, spirituality or belonging-in-the-world is likely to be a concept that evolves over the course of therapy since its intersubjective qualities will cause the meaning to change over time as worlding is constantly shifting. Therefore this is likely to be a topic that needs to be discussed over the course of therapy, rather than assessed at the beginning of therapy and assumed to be static.

4.2.3 Appropriateness of existential therapy

May (1983) suggests that psychology built on the Cartesian subject-object duality has separated human reality from its foundations. Existentialism attempts to study human beings in their own reality avoiding the compartmentalisation and dehumanisation of modern culture (May, 1983). Thus according to May (1983) existentialism is an endeavour to grasp the reality of being-in-the-world. Henceforth, existential therapy is often considered a clarification of what it means to be alive (van Deurzen, 2002). Arguable the central theme of existential therapy is death (Yalom, 1980). Death is the great leveller to which everything else is played out against (van Deurzen and Arnold-Baker, 2005), and therefore existential therapy aims to help individuals confront their guaranteed mortality (Yalom, 1980). Working with people with advanced cancer therefore seems very appropriate to the existential philosophy of therapeutic practice. This approach allows individuals to explore meaning from their interrelatedness with the environment. Therefore existential therapists can explore the individual's meaning in terms of their experience of spirituality or belonging-to-the-world.

A further consideration when discussing working with individuals at the end of life is the appropriateness of the different types of group or individual therapy. As discussed

in the introduction, Greenstein and Breitbart (2000) ran a meaning-centred group for people with terminal illnesses. The group explored individual meaning of day to day activities within the context of Frankl's (1962) *Man's Search for Meaning.* From looking at the data collected from this study, it seems that individuals in the everyday mode of being may benefit most from having this type of therapy since their belonging-in-the-world was focused on connections with other people and the environment. Greenstein and Breitbart (2000) found that all individuals in the group also put relationships at the top of their list of meaning and emphasised the importance of connecting with others. Perhaps therefore the participants in this group had a similar worldview to those in the everyday mode of being. In contrast the participants viewing life in the transcendent mode of being stated that they were withdrawing from other people and seeking solace in their inner world. Therefore for these people, perhaps a more philosophically orientated group discussion would be more appropriate rather than focusing on everyday tasks. Also creative methods of therapy such as reading, music and art may enhance the therapeutic process for individuals in the transcendent mode of being.

4.2.4 Learning, practise and training

Given the importance of spirituality or belonging-in-the-world demonstrated in this study, it is vital that Counselling Psychologists working in the field of palliative care gain some training in these issues. To start working on spirituality without any formal training may lead to therapists contaminating the relationship with their own beliefs and reacting in an unbounderied way to the client's material. Additionally, not being aware of how to work with spirituality may mean that this important topic is left unexplored, or the therapist feels ill-equipped to investigate it in more detail. Spirituality is not a subject that is covered in Counselling Psychology training programmes, and therefore for professionals in this field it is important to attend additional learning on this area. This could be filtered back into the multidisciplinary team as part of the Counselling Psychologists role.

Jacobsen (2005) argued the importance of knowing your own beliefs in order not to contaminate the therapeutic alliance. Therefore encouraging therapists to think about these issues in personal therapy and training is likely to help them solidify their own

thoughts on the subject. In addition it could be useful to have a discussion group among therapists and healthcare professionals, such as White's (2000) group for spiritual care, to explore these issues further. Furthermore, therapists working with spirituality should bring their cases to supervision to further ensure that the therapist is able to reflect on the material being explored in therapy.

4.3 Evaluation of the Research Process

4.3.1 Strengths of the research process

Exploring the experience of "spirituality" and meaning-making in advanced cancer has been a challenging area of research. However, by adopting a phenomenological approach, it was possible to encourage individuals to be free in their descriptions of the phenomenon without having to conform to any preconceived notions of spirituality. Comparing this process to my previous experience of handing out questionnaires, I felt participants were more engaged in the research, which lead to more valid findings. This was confirmed by the fact that all individuals who had a second interview felt their summary of the interview were accurate and captured their experience. Although the analysis demonstrated that for some individuals the term "spirituality" is not appropriate, this is an important finding which may not have been discovered if I had imposed the term in the interviews assuming that it was relevant for everyone. Consequently, a significant conclusion was made that we should use only terminology that correlates with the individual's experience. The validity of the study was also increased by being transparent about the conflicts and difficulties in deciding what constituted "spirituality". Thus the reader can follow the dilemmas in the research and evaluate the process. Previous studies have not revealed the decisions behind terming an experience "spiritual", which leaves the reader in doubt as to whether this is an accurate reflection of the participant's experience.

Another strength of using a phenomenological approach, is that the method allowed the intersubjective qualities of spirituality/belonging-in-the-world to emerge. The interviews were analysed within the context of the persons "throwness" which allowed for more detailed analysis. If a method assuming Cartesian subject-object

duality such as questionnaires had been used, it is likely that the data would not have been as rich. Similarly, using a hermeneutic phenomenological method of analysis allowed creativity in viewing the data which was vital for such an elusive concept. Writing and rewriting the results allowed more insights to emerge without the pressure of trying to code the data into themes. Furthermore, transcribing the narrative using poetic condensation retained the expression in the participant's interviews. I feel this is successful in allowing the reader to engage both cognitively and emotionally with the narratives.

Given the emphasis on intersubjectivity in phenomenology, this approach allowed me to consider the relationship between myself and the participants created during the research. By keeping a reflexive diary and considering my position in relation to the research I was able to consider how my characteristics and interests contributed to the data I collected. Thus I was able to more accurately reflect the experience of the participants by taking into account my relationship with both the participants and the research in the analysis.

4.3.2 Limitations of the research process

The concept of "spirituality" is likely to have many other meanings in other cultures. Therefore, it is important to bear in mind that this research took place in the UK and therefore findings and recommendations for therapy may not be relevant for other countries. Ideally, the sample would have been more homogenous to allow a greater illumination of a particular experience that is common to all participants. I had attempted to recruit a homogenous population in terms of their life expectancy and diagnosis of cancer. However, although individuals were in a similar stage of their illness there was great variety in the way that the individuals had processed their diagnosis of cancer. The hospice staff judged the stage of the individual's illness, so perhaps a more homogeneous sample would have been achieved if individuals had identified themselves in the advanced stages of cancer. Furthermore, I suspect from the interviewees comments that individuals agreed to take part in the interview to return the gratuity they had received from the hospice. Thus it is not clear if the participants identified themselves as "spiritual" or if they felt they should take part in the research when the staff approached them because they felt they had gained so

much from the hospice. Nevertheless, finding out that some people did not connect with the term "spirituality" was still useful data.

The final limitation is applicable to all phenomenological research; the method relies on participants being well educated and eloquent in describing their experience. This is particularly an issue for researching "spirituality" since the concept is vague and difficult to conceptualise. Consequently, those participants that were able to express themselves clearly provided richer data in comparison to those less able to verbalise their ideas. This is a difficult problem to account for, but perhaps it would have been useful to have supplemented the data with other sources of data such as observation, art work and diaries. This was not considered when designing the methodology in order to reduce the burden on participants who are physically ill. However, this could be used in the future as it was found that all participants were willing to take part in the study, and no one considered the research a burden.

The final quotes in the analysis were quite different from the raw verbatim in the interviews. As mentioned previously, keeping a reflexive diary and considering my relationship with the research and the participants allowed me to evaluate the analysis and stay true to the phenomena that were observed. However, it would have also been useful to present the poems to the participants for verification.   This was not considered when designing the research given the time taken to transcribe and convert the data into poems and the limited time left for participants. However perhaps a future consideration would be to create the poems together with the participants in order to increase the validity of the research and strengthen the co-researcher relationship.

4.4 Personal Observations and Final Conclusions

From conducting the interviews with the participants it is clear that spirituality and belonging-in-the-world are very important to the person with advanced cancer. However, it seems that all participants felt that people who are well may not

understand how they are feeling. In terms of belonging-in-the-world it might be easy to miss the significance of everyday tasks. I realised early on in the research that I had done myself when I was surprised that this was a relevant topic to the research. This lead me to wonder how often people misunderstand the importance of what could be considered small or minor activities, and the distress that comes from feeling isolated from the world. It is also possible that people misunderstand the need withdraw for individuals in the transcendent mode of being. From the interviews it seems that the people in their lives felt more comfortable getting the individual to do something to improve their health, perhaps with the fear that not doing anything is tantamount to giving up. However, for these individuals accepting death and allowing the dying process to happen was extremely important for them and something that not many people allow them to do.

As the interviews progressed I became more familiar with the different ways of viewing life when facing advanced cancer. Consequently the later interviews flowed more easily and I was able to acknowledge what was important to the individual without being surprised or questioning if this topic was relevant to the research question. I feel that this reveals an important lesson for Counselling Psychologists working in the field of palliative care. For individuals who have more of an everyday worldview, it is important not to trivialise the importance of day-to-day activities. It might be appropriate for therapy to focus on enabling clients to interact with their world and process the distress that comes from their limited physical abilities. For individuals operating within the transcendent mode of being, it is important to accept the dying process of the individual and not encourage them to have to do anything. Therefore it might be more suitable in therapy to embark on a philosophical discussion about the overall meaning of life without necessarily focusing on future goals or tasks.

Working with death in therapy can be very emotive and I found myself not wanting to finish the interview and let go of the participant. This process has highlighted the importance of supervision and personal therapy in order to unravel the therapist's reaction to death and to ensure that the person is allowed to discuss their own meaning without having another person's view imposed onto their world.

4.5 Future Directions

Research into the physical and psychological benefits of "spirituality" seems to have accelerated before anyone has really captured what the concept means. This study has shed light on what "spirituality" means for some participants, and for others has demonstrated that "spirituality" is not a term that is useful for everyone. However, this is only the beginning of qualitative research in this area and thus there are a plethora of avenues that need to be explored further. For example, it would be helpful to research participants from different countries to explore the concept of "spirituality" in a range of languages and cultures. Also although much of the research in "spirituality" has been conducted on the palliative care population, it is not a concept that is exclusively relevant to these participants. Therefore, it would be helpful to explore the experience of "spirituality" in other populations such as those with enduring mental health issues, chronic health problems or people who have experienced bereavement. Finally, it would be useful to look at case studies of existential therapy exploring the experience of spirituality/belonging-in-the-world to help therapists learn how to explore these issues in the therapeutic process.

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PART III

DOES PSYCHODYNAMIC THERAPY BENEFIT
PEOPLE WITH DEMENTIA?

6.1 Overview

Since Kitwood (1993) argued that dementia care should look beyond the medical model of treatment there has been an increased interest in psychotherapeutic techniques for working with people with dementia. There are a number of models that could be appropriate for people with dementia, such as cognitive-behavioural therapy and person-centred therapy as well as both group and individual work. This review examines the benefits of using a psychodynamic approach for clients with dementia. A number of authors have contributed to the psychodynamic theory of dementia, but it still remains to be shown if this approach benefits the client. Six studies are explored with the intention of illuminating the findings in this area. A number of methodological issues are raised within this client group, with a particular focus on the issue of how to assess the outcome of therapy with a client who may not be able to give specific feedback to the therapeutic practice. Some suggestions are made about adapting therapy for this client group as well as considerations for future research in this area.

6.2 Review of the Treatment for Dementia

6.2.1 What is dementia?

Dementia is an umbrella term for a set of symptoms caused by a degenerative disease of the brain, such as Alzheimer's disease or Vascular Dementia. The main features of dementia are loss of memory, confusion, impaired speech and difficulty carrying out activities of daily living. In the later stages of dementia the person may become incontinent and unable to eat, speak or mobilise. Each person with dementia will experience different symptoms, and disease progression will depend on physiology, emotional resilience and support available (Alzheimer's Society, 2002). Recent Department of Health statistics have suggested that dementia occurs in one in twenty

people over the age of sixty-five and one in five people over the age of eighty (Department of Health 2001), and that figure is expected to rise.

Not only does dementia have a profound physical affect on a person, by psychologically receiving a diagnosis of dementia is a frightening time, often leading to feelings of fear, distress and devastation (Weaks, McLeod and Wilkinson, 2006). In addition to facing the prospect of a slow decline and eventual death, the stigma surrounding the label of dementia causes embarrassment and secrecy (Weaks et al., 2006). As a result coping with a diagnosis of dementia can be extremely difficult (LeBarge, 1981).

6.2.2 Treatment for dementia

Historically treatments in dementia have been largely influenced by the medical model, and thus the majority of research has investigated psychopharmacological options. Drugs such as Donepezil and Rivastigmine have been shown to postpone severe impairment (Bates, Boot and Beverley, 2004). However these drugs have not been effective in all people with dementia and issues such as poor compliance and side effects have been reported (The National Institute of Clinical Excellence; NICE, 2001).

Kitwood (1993) argued that dementia care should look beyond the medical model and open the channels for treating the emotional needs in people with dementia. Kitwood viewed dementia as an interaction of neurological impairment as well as personal and social psychology (Kitwood and Bredin 1992). He proposed that there is a "malignant social psychology" surrounding the person with dementia, such as dehumanisation, intimidation and stigmatising, which stripes the individual of their 'personhood' and potentially increases their rate of decline (Kitwood, 1993). Although care givers may have good intentions, by objectifying the person with dementia and talking over them, their social world dies around them along with their motivation to participate (La Barge, 1981). Kitwood and Bredin (1992) therefore promoted accepting the person with dementia as an individual who has the same human needs as the rest of society. Thus according to Kitwood and Bredin (1992)

any approach to dementia care should encourage individuality, dignity, self respect, choice and independence.

Previous psychological interventions which have received some empirical support include Reality Orientation (eg Holden and Woods, 1995), Reminiscence Therapy (eg Scogin and McElreath, 1994) and Validation Therapy (Feil, 1992). However Woods (1999) argued that many of these therapies do not value the personhood advocated by Kitwood (1993). Reality Orientation, where the person with dementia is given facts to orientate them in time, place and person has been criticised for being too mechanical and depersonalised, and risks infantilising the person with dementia (Woods, 1999). Also Validation therapies, which aim to resolve 'unfinished business' in the person with dementia's life by responding to the emotional content of communication, have also been rejected by some authors given that there is no evidence that people with dementia have conflict in their past (Cantley, 2001).

6.2.3 Psychotherapeutic interventions for dementia

The use of counselling and psychotherapy to deal with emotional issues in dementia has been steadily increasing over the years. Weaks et al. (2006) commented that although counselling will not cure dementia, it may help the person come to terms with changing roles in relationships, the stigma of diagnosis, addressing philosophical questions and making sense of their changing world. Kitwood and Bredin (1992) even claimed that some patients have experienced 'rementia' where social skills, independence and continence have improved as a result of therapy. However, they acknowledge that this evidence is anecdotal and there needs to be systematic study in this area.

There have been many different models of therapy applied to working with people with dementia. Teri and Gallagher-Thompson (1991) demonstrated that cognitive-behavioural therapy can be useful when working with people who are depressed in addition to their dementia. Person-centred counselling is thought to be beneficial in helping people with dementia express their emotions in a safe and supportive environment (e.g. Solomon & Szwabo, 1992). Cheston and Bender (1999) suggest that psychodynamic therapy is appropriate for people with dementia that have a

reasonable cognitive competence and a relatively health pre-morbid psychological status. The purpose of the current review is to investigate whether psychodynamic therapy is beneficial with this population. However this is only one type of therapy and therefore it would be useful to review other methods of working with people with dementia, such as CBT or person-centred therapy, in future research.

6.2.4 Psychodynamic theory and dementia

Psychodynamic therapy has evolved from the work of Freud (1856-1939), who maintained that our central identity, the ego, constantly defends against anxiety in order to limit distress. The focus of psychodynamic therapy is to bring distressing feelings into consciousness given that defence mechanisms, such as denial and repression, often cause more harm than good. The therapist explores a persons behaviour in terms of their internal structures and the client's relationship with significant others using tools such as transference and countertransference (Jacobs, 2004).

According to the psychodynamic approach, the ageing process invariably triggers unresolved issues (usually some form of loss) to re-emerge, making demands on the resources of the ego (Schmid, 1980). Weiner (1991) argues that these unresolved issues are particularly damaging in dementia given that the ego strength is reduced due to impairments of the ego function (i.e. thought, memory, speech and perception). Since the person with dementia lacks energy to cope, the ego employs classic defence mechanisms, such as splitting, projection and regression, to conserve energy by allowing partial discharge of drives (Weiner, 1991). For example a person with dementia may blame someone else when they have forgotten something, or believe that a dead relative is still alive. Raw drives may also emerge, such as inappropriate fondling and genital display, when sublimation becomes more difficult. These coping styles are considered to reflect the individuals pre-existing ego structure (Cheston, 1998), and will uncover parts of personality that were partially suppressed when the individual was well (Weiner, 1991).

The psychodynamic theory of dementia claims that eventually the defence mechanisms will begin to fail, increasing anxiety and confusion causing the person

with dementia to become unable to deal with multiple environmental stimuli (Cheston, 1998). As the ego becomes more overwhelmed, the person may experience catastrophic reactions such as delusions and hallucinations. Thus the person with dementia struggles to maintain a sense of self leading to feelings of helplessness and fear causing them to become increasingly dependent on others and need constant reassurance (Kasl-Godley and Gatz, 2000). The theory postulates that without the self awareness to develop compensatory mechanisms, the person with dementia will become fixated on the past issue and is unable to mourn appropriately and move on (Cheston, 1998). The aim of the therapist is to slow the process of ego loss by recognising and validating the client's competencies and essentially becoming a new ego in order for the person to cope with conflict (O'Connor, 1993). Kitwood and Bredin (1992) have likened this process to holding together the shattered pieces of the person's personality structure.

Although the psychodynamic model provides a theory of the symptoms of dementia, the question remains if psychodynamic therapy is beneficial with this client group? Freud (1924) assumed that older adults do not possess the psychological resources for psychodynamic therapy and therefore this client group was neglected for a long time. However, more recent research has shown that the elderly are in fact responsive to psychodynamic therapy, and can demonstrate cognitive resources, capacity for introspection and the ability to develop therapeutic alliance (Cath, 1982). However, therapists and family still question the use of psychodynamic therapy in elderly persons with dementia (Hausman, 1992). Of particular concern is whether insight is helpful for a person with dementia as it is possible that denial and projection are the only way of dealing with losses, and to gain insight would only increase anxiety and distress (Cheston, 1998).

6.2.5 Methodological issues in assessing therapies for dementia

There is a lack of literature evaluating psychotherapeutic interventions for people with dementia. Cheston (1998) conducted a meta-analysis of the literature and found that the majority of the research in dementia care has consisted of anecdotal reports, which sometimes are no more than a few comments. Systematic reviews often lack validated outcome measures, control groups, and frequently involve only a few

participants (Cheston, 1998). Further more Bates, Boote and Beverley (2004) found that most studies do not distinguish between different stages of dementia which is likely to lead to a performance bias and limit the generalisability of the results.

This is a difficult area of research to pursue due to the difficulties of measuring outcomes from people with cognitive impairment. In addition researchers may be reluctant to explore interventions for participants who will continue to decline despite the therapeutic technique. Thus the results are unlikely to show an 'improvement'. The general hesitancy to research therapy for people with dementia is revealed in the following quote; *'Doing research with individuals is extremely difficult. We commend investigators who have initiated research with the population'* (Marshall and Hutchinson, 2001; p493). However, although this is a difficult area this should not be a reason to abandon the topic. Instead there should be careful consideration of how to approach a methodological challenging area of research.

6.2.6 Purpose of the literature review

The following literature review is concerned with examining whether psychodynamic therapy is beneficial for people with dementia given their declining cognitive abilities. Thus it will be considered if psychodynamic therapy is an appropriate model for dementia and how the clients reacted to therapy. Sinason (1995) has suggested that people with dementia may have an emotional intelligence left intact regardless of their cognitive deficits. However Greenwood and Loewenthal (1998) wonder if there is a point when people with dementia have declined so much that they are not able to function in a relationship. It is expected that an examination of research in this area will highlight the difficulties in the therapy for both the client with dementia and the therapist. Also the methodological issues of conducting the research in this challenging area of Counselling Psychology will be explored. It is hoped that the findings of this review will inform the future practice of Counselling Psychologists working with people with dementia. Furthermore the current review is hoped to inform future research in this area.

6.3 Reviewing the literature

There is a lack of literature examining the benefits of psychodynamic counselling in dementia. The following six studies represent the entirety of the published research in this area and mainly consist of case studies. At present there only appears to be one systematic review of the benefits of psychodynamic counselling in dementia.

6.3.1 Akerlund and Norberg (1986)

The first formal review of psychodynamic therapy was reported by Akerlund and Norberg (1986), who compared the cognitive and emotional functioning in five people with dementia who received a course of Reality Orientation followed by a course of psychodynamic therapy. The sessions lasted for one hour and were conducted four times a week. The therapeutic outcome was measured by the therapists as retrospective qualitative observations. The raters concluded that participants demonstrated higher cognitive levels during the psychodynamic sessions than in Reality Orientation.

Although the results suggest that psychodynamic therapy produced higher levels of cognitive ability than Reality Orientation, there are a number of methodological problems with this study. Firstly neither condition is described and the duration of therapy is unknown making replication extremely difficult and the reliability questionable. Also there does not seem to be any formal system for rating the person with dementia's cognitive abilities and thus it appears to be up to the subjective judgement of the therapist. Furthermore the fact that the therapists were making these judgements is likely to further bias the results given that their expectations of the group may have influenced their results. Also taking the measurements retrospectively may have further reduced the validity of this study since the therapist's memory of the client's behaviour may not be as accurate after the therapy. A more effective approach may have been to have an objective observer take notes during the session using a standardised technique.

Since this study it has been recommended to abandon comparing one treatment compared to another since there is no consensus on what treatments are best in dementia care (Cheston, 1998). Instead the Department of Health (1996) suggests

that clinical techniques should be described systematically through case studies first and then examined through systematic reviews.

6.3.2. Hausman (1992)

Hausman (1992) reviewed three case studies and measured the success of each client from their achievement of ten goals: to be in a caring relationship; having an emotional outlet; enhancement of self esteem; minimisation of psychological and behavioural problems; increase in coping skills; enhancement of role functioning; a sense of control; ability to grieve over losses; development and maintenance of most mature and productive defences possible; and development of insight. According to Hausman (1992), attaining these goals depends on the stage of the disease, premorbid psychological sophistication and the point at which the therapist and person with dementia start working together.

The first case of Mr M, where Hausman (1992) was the therapist, was documented as an example of when psychodynamic therapy is not appropriate. Mr M's wife had reported some recent bereavements but when Hausman (1992) mentioned this, his speech difficulties became worse and he could not express himself. Mr M consequently became frustrated and depressed and Hausman (1992) decided to terminate therapy since they had not had a chance to develop a relationship of trust, one of the first goals of therapy, before the dementia became severe. Hausman (1992) reasoned that to continue the sessions may have resulted in Mr M associating the office with low self esteem and an inability to cope, and thus the decision was made that it would not be in Mr M's best interests to continue therapy.

Hausman (1992) reported a more successful case study of Mr D, a 74 years old man with a diagnosis of dementia who worked with a supporting therapist. The therapist noted that Mr D's wife seemed extremely reluctant to let him go to therapy, and at times sabotaged appointments by 'forgetting'. However his wife later reported that Mr D was calmer, more at peace and cognitively more competent. The therapist who worked with Mr D felt that Mr D had demonstrated transference by associating the therapist with a previous therapist that he had seen forty years ago. The current therapist was able to reconstruct material Mr D had discussed in the previous therapy

and considered a decrease in agitation as a marker for "striking the right chord". Mr D was able to grieve over the loss of his first wife, and his cognitive capacities, such as negotiating public transport, appeared to last longer than would be expected. Hausman (1992) considered this to be a result of increased self esteem from engaging in therapy, as attending appointments was an achievement in itself indicating his continuing independence. The therapy was deemed to be beneficial since Mr D attained the first three goals, as well as using defence mechanisms and demonstrating coping skills.

The case of Mrs K, who worked with Hausman (1992) was also considered to be a productive use of psychodynamic therapy. According to Hausman (1992) Mrs K quickly experienced transference, projecting feelings towards her deceased daughter onto Hausman. During the course of therapy, Hausman (1992) learnt Mrs K's stories which she used to explore feelings when Mrs K could not initiate them herself. It was concluded that Mrs K achieved at least the first three goals of therapy, although the positive effects of therapy became shorter towards the end of Mrs K's journey with dementia. However, Hausman continued to visit Mrs K in order not to become another one of her losses.

Although Hausman (1992) does not describe in detail how she and her supporting therapist conducted the psychodynamic therapy, she raises some suggestions for working with people with dementia in this model. For example, she recommended that therapists repeat stories back to the client to show that they have been heard, and are maintaining a perception of the client as they wish to be viewed. Also sessions should be consistent, being held in the same place and time of day that is best for the person with dementia and it may be necessary to bring other materials into session to prompt memories, such as pictures, maps and diaries.

The case studies reported by Hausman (1992) provide initial support for the benefits of psychodynamic therapy for with people with dementia provided that the therapy starts relatively early in the disease process. However, it is not clear exactly what stage is early enough, although this is likely to vary with the individual. The case studies summarised above are widely quoted in dementia literature as demonstrating the efficacy of psychodynamic psychotherapy. However the goals of therapy have

not been standardised and there is not an exploration of how Hausman (1992) decided that the clients had attained the aims on her list. Kitwood and Bredin (1992) have proposed twelve indicators of well being, validated by both people with dementia and dementia experts which could be used as an alternative to Hausman's (1992) goals. These indicators include: demonstrating assertiveness; bodily relaxation; sensitivity to needs of others; humour; creative self expression; showing pleasure; helpfulness; initiating social contact; showing affectation; self respect; expression of a range of emotions; and an acceptance of other dementia suffers. These makers could have been assessed by an objective observer in addition to Hausman (1992) to reduce any bias from the study.

6.3.3 Jones (1995)

Jones (1995) describes the application of Sullivanian informed psychodynamic therapy for a person with dementia. Sullivan's theory (1953) views interpersonal behaviour as functional, and therefore, although it may not be conventional, behaviour in dementia is still meaningful. The therapeutic task thus consists of understanding the meaning of behaviour in a person with dementia particularly as the capacity for reflection declines and anxiety becomes expressed through motor reactions.

The therapist (it is not clear if this was Jones or another therapist) worked with Mr G, an 82 year old retired educator who was diagnosed with mild multi-infarct dementia characterised by impaired memory, cognitive abilities and visuospatial skills. Mr G was very aware of his deficits and became distressed and suicidal. He attended twice weekly Sullivanian therapy during a 3 month hospitalisation period which reduced his depression despite variation in his cognitive abilities. After three months at home, he returned to hospital in a state of increased confusion. Mr G again attended therapy which focused on exploring how dementia impacted his life. After two months Mr G was placed in a community home and continued outpatient therapy. The treatment during this time consisted of a life review, examining his relationship with his parents, wife and children, and his concerns about his future. After six months in the group home he became agitated and was placed in a locked dementia ward. His therapy continued and both Mr G and his daughter commented on how much his mood and isolation improved in therapy.

Jones (1995) concluded from this case study that Sullivanian therapy can be beneficial to clients are unable to cope with escalating cognitive and social losses. However, as with Hausman's (1992) research, the case lacked a standardised measure of outcome. Mr G's depression was measured using vegetative signs and subjective dysphoria, but details of how this was obtained are not given. Therefore the strength of the conclusions are limited, and Jones (1995) admits that the use of this type of therapy in dementia needs more rigorous empirical support.

Another consideration is whether Mr G benefited from psychodynamic counselling per se, or whether it was the general support of the ongoing therapy. In the case study he was moved four times, from his home, to hospital, to a group home to a locked ward. Given that people with dementia are less able to cope with multiple environmental stimuli, and generally become more anxious in unfamiliar settings, it is possible that the increased affect and reduction in isolation reported by Mr G was a result of having a consistent, familiar face and therapy setting when everything else in his world was changing and confusing. Therefore it may be useful to analyse the use of this therapy on a client with a more stable environment to see if the same benefits are gained.

6.3.4 Sinason (1995)

Sinason (1995) presented the case of Edward Johnson[3], who was been diagnosed with Alzheimer's disease aged 56 and at the height of his profession in university academia. Mr Johnson's GP had referred him for psychotherapy due to his concerns about the devastating emotional impact dementia had on Mr Johnson's well being. Sinason (1995) visited Mr Johnson at home since his memory had declined to the point where leaving his house to go next door would cause disorientation. This raised several boundary issues for Sinason (1995) since she had to be wary of privacy and when the patient was consenting to treatment.

During the course of the sessions Sinason (1995) tried to understand the meaning of Edward Johnson's words. For example in the first contact, he said he was lonely, but

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[3] A pseudonym

given that he had many friends. Sinason (1995) deduced that he meant he was lonely inside. When reflecting that he wanted to move in with his friend, Mr Johnson replied "dead right", which Sinason (1995) interpreted as a sign that he missed his deceased wife. When Mr Johnson replaced the word 'Sussex' with 'suspect', Sinason (1995) thought he was wary of his friend who was not offering to live together. She also thought that Mr Johnson was 'suspect' of her since Sinason (1995) was not helping him to gain his memory back. As his Alzheimer's progressed Mr Johnson became angry and frustrated and expressed suicidal ideation. Towards the end he did not recognise Sinason and therapy was terminated when he said that he wanted to concentrate on his gardening.

Sinason (1995) appears to make quite a leap in her interpretations, in the absence of any feedback that she is correct. There are numerous reports that the language of people with dementia is rich in metaphors (Cheston, 1998), but is it possible for an outsider to interpret these metaphors? Laing (1972) argues that we can only experience our behaviour from within ourselves and not from inside another. In contrast, Cheston (1996) maintains that we can understand the meaning of a person with dementia's communication if we can only allow ourselves to listen to the poetical metaphorical aspects of language. Sinason (1995) commented that her role as therapist acted as compensation for the immediate intellectual losses that Mr Johnson had experience: *"it felt to me that one of the functions of working with a deteriorating patient was to hold their memory, their knowledge, their choice of word"* (Sinason, 1995; p.99). However Greenwood and Loewenthal (1998) argued that Sinason's (1995) motivation to find meaning for Mr Johnson's words came from her difficulty in being in a position of not knowing. They suggest that giving the client meaning to their words takes away the client's right to acknowledge their own meanings and therefore is akin to disintegration of the ego; *"By giving the client her meanings she takes away the right he has to his and maybe the acknowledgement that these meanings are impossible to discover, even for the subject themselves"* (Greenwood and Loewenthal, 1998; p. 288).

It is not clear from Sinason's (1995) account whether Mr Johnson benefited from therapy since there is no clear evidence that Sinason's (1995) interpretation of Mr Johnson's meaning relieved any of his distress. However she concluded that Mr

Johnson had his emotional intelligence intact despite severe cognitive impairment. In working with the emotional content of his communications, Sinason (1995) reflected that the therapy was supportive but not transformational, raising the possibility that it had been the relationship that was more beneficial than the model of therapy.

6.3.5 Greenwood and Loewenthal (1998)

Another case study was described by Greenwood and Loewenthal (1998), who were interested in finding out if psychodynamic therapy was possible with a person with dementia. Greenwood, who was also the therapist, found during the sessions that he was heavily influenced by the research question rather than the therapeutic relationship. He missed the first session with Des, which he realised was due to his complacency that Des would not remember the appointment. From the first contact Greenwood attempted to put meaning into Des's communication. For example when Des opened and closed a magazine and rubbed the cover saying "gently", Greenwood considered that the cover represented Des's outward appearance and he was taking time to find the attractive person beneath the surface. By the third session Greenwood realised that he was unable to give Des his full attention since trying to find meaning was making him exhausted. Greenwood questioned why he was trying to find meanings since Des never confirmed if he was correct. As a result Greenwood became less concerned with meaning and concentrated on the relationship. The therapy became more enjoyable and Des referred to Greenwood as "Good Buddy". It isn't clear at what stage the therapy was terminated or how this was decided.

The lethargy Greenwood felt during sessions and carelessness in regard to appointments could be regarded as signs of countertransference. Kaplan (1990) noted that working with people with dementia can raise deep emotions as a result of their own fear of ageing and resonance with other loved ones who may be in a similar situation. Not being aware of countertransference can put the therapist at risk of behaviours that are unhelpful to the client. When unusual emotions are noticed, Kaplan (1990) recommends exploring these issues with a supervisor or peers to discover the meaning of a reaction. Greenwood's apparent countertransference in the case of Des raises further issues about the researcher also being the therapist. It is

possible that Greenwood's negative reaction to Des resulted in a more pessimistic attitude towards the therapy.

Greenwood and Loewenthal's (1998) objective from the case study was to see if therapy was possible. No attempt was made to review if Des had benefited from the therapy and Greenwood admitted that he had attempted to 'use' Des in order to find the answer to his research question. This raises the question of who exactly the research is aimed to help, and if the therapist is able to make objective opinions about the benefits of therapy as a researcher. It seemed that once Greenwood concentrated on their relationship rather than the research Des responded more to the therapy. Thus it is not clear if having a supportive relationship is just as effective as psychodynamic therapy, or if Greenwood was more effective at delivering this model of therapy when he prioritised their work together over the study.

6.3.6 Burns, Guthrie, Marino-Francis et al. (2005)

The first systematic review of psychodynamic therapy in people with dementia was conducted by Burns et al. (2005). The study was a randomised controlled trial aimed at investigating if people with Alzheimer's disease could benefit in cognitive functioning, affective symptoms and global well being as a result of psychodynamic counselling. All participants had a diagnosis of mild dementia (scoring more the 15 on the MMSE; Folstein, Folstein and McHugh,1975), lived at home, had a carer in regular contact and were able to communicate verbally. Participants were randomly allocated into treatment or no treatment group.

Twenty participants were recruited for each group and were randomised into treatment or no treatment groups. The treatment group received six sessions of one-to-one Brief Psychodynamic Interpersonal Therapy with a therapist who was not an author. The aim of therapy was to identify interpersonal conflicts which were causing or maintaining distress (Brierley, Guthrie, Busby et al., 2003). Sessions were conducted at home since it was considered that the individual would function better in familiar surroundings, as well as giving the therapist an accurate picture of the client's level of impairment. At the end of each session five to ten minutes was spent with the carer to assess their relationship and to gain more insight into the person with

dementia's difficulties. In the no-treatment group participants received advice about the diagnosis and treatment for people with dementia.

All participants had been informed of their diagnosis, although some referred to this as memory loss rather than Alzheimer's disease. The therapy was aimed at creating a dialogue for the clients to discuss these feelings should they wish to do so, and was not aimed to push them into a confrontation. All but one client was able to discuss their frustration, fears and sense of loss. Some of the participants were angry, whereas others shared fears of their cognitive decline and what would happen if their carer were no longer present. Many of the participants expressed relief at being able to talk about the future. The therapist explored the 'denial' in the few of the participants who were not able to accept their diagnosis. One female maintained that she was a volunteer for the programme, and questioned the therapist about her qualifications and previous experience. She refrained from discussing emotional material but reported that she found therapy extremely useful. Towards the end of the sessions she mentioned the "slow march of Alzheimer's" but the therapist considered her to be in partial denial.

An important function of the therapy was increasing self worth since the majority of participants had a reduced self esteem (Burns et al., 2005). This was achieved by helping the people with dementia look at positive qualities they had demonstrated in the past and to make links to the present to show that they are still the same person. Also the therapist helped the clients review reactivated past conflicts and explore ways of coping in the present. The sessions also encouraged practical changes, with a particular emphasis on improving relationships with family and friends, which is a move away from traditional psychodynamic therapy.

Assessment of the treatment was carried out at baseline, after six weeks and then after three months. The tools for assessment included the Cornell Scale for depression (Alexopoulos et al. 1998), MMSE (Folstein et al., 1975), Revised Memory and Behaviour Problems Checklist (Teri, Truaxm, Logsdon et al., 1992) and the Bristol Activities of Daily Living Scale (Bucks, Ashworth, Wilcock et al., 1996) which were all completed by the carer for the person with dementia. The carer also completed assessments for themselves such as the General Health Questionnaire (Goldberg and

Williams, 1985), Beck Depression Inventory (Beck, Ward, Mendelson, et al. 1961) and Ways of Coping Checklist (Vitaliano, Russo, Carr et al., 1985). The results revealed no significant change on any scale, although there was a slight improvement in carer's reaction to behavioural problems. Every participant agreed with the statement 'I was able to discuss my difficulties with my counsellor and become more clear about what they are' and other comments included 'I was able to confide and talk easy in a friendly way', 'she drew out some points I had never realised' 'it was beneficial but I don't know why'. When the treatment group was visited six to twelve months later, all participants could remember the therapist but most could not remember the content of the sessions. The five who did recall the sessions said they had found the therapy helpful.

The authors concluded that psychodynamic therapy could be adapted for people with Alzheimer's Disease, although they were not able to show conclusively that participants benefited from the therapy. It is possible that the therapy was too short to result in any major improvements. Burns et al. (2005) acknowledge this limitation and claimed using brief therapy was an initial investigation to see if they could justify a more intensive approach. The qualitative statements made by the people with dementia after therapy provide support for the psychodynamic model and substantiate the need for further research in this field. However, since all participants were in the early stages of dementia, these results cannot be generalised to moderate and severe dementia.

White (2006) criticised the authors for biasing the outcome of the treatment group since the non treatment group were not asked about their experience or followed up. Given that the non treatment group were receiving multidisciplinary support they too may have made positive statements about the care they received. A more thorough comparison between the groups would therefore be needed to conclude if it was psychodynamic therapy that helped the people with dementia, or supportive care.

The scales used to measure depression, behavioural problems and functioning (ie Cornell Scale, Revised Memory and Behavioural Problems Checklist and the Bristol Activities of Daily Living scale) are all measurements that were rated by carers. Therefore the results from the carers could have been biased since family members

often try to protect the person with dementia by not discussing impairments (Roper-Hall, 1987), and often carers are so desperate to see improvements that they overestimate standardised measurements (Brooker, 2001). Bond and Corner (2001) argue that if researchers are to take personhood seriously they should demonstrate a commitment to viewing beliefs and experiences from the perspective of the person being studied. Since the inclusion criteria meant only people who could communicate verbally were included in the study, there seems to be no reason why the person with dementia could not contribute to rating their improvement. If the participants were unable to complete scales themselves, more in depth qualitative work could have supplemented the results.

6.4 Conclusions

6.4.1 Problems with the literature

Reviewing the literature has highlighted a number of methodological challenges of researching the benefits of psychodynamic therapy in people with dementia. Most of the research relies on a case study method, which is considered the most eminent way for scientific validation in psychodynamic therapy (McLeod, 1993). However, given that the person with dementia may not be able to comment on how beneficial they found the therapy to be, the case study approach causes a number of problems when assessing the outcome. Studies such as Hausman (1992) and Sinason (1995) are open to bias given that the researcher is also the therapist. Without having any feedback from the clients or concrete statements about whether they found therapy was helpful or not, the judgement on outcome is entirely based on the researcher's opinion. This is likely to be informed by their own experience of the therapy, which could be influenced by countertransference issues as found in Greenwood and Loewenthal (1998) study. Perhaps therefore it would be useful to supplement the findings with observational data. For example making note of Kitwood and Bredin's (1992) twelve indicators of well being before, during and after therapy may help validate the findings of the research.

Another issue that emerges from the literature is how 'psychodynamic' is the therapy? Many of the studies do not discuss the process of the psychodynamic therapy leaving it unclear as to how they worked with the client. Greenwood and Loewenthal (1998) claimed that they concentrated more on the relationship rather than interpretations, which seems to resonate more with a supportive role rather than psychotherapy. Also Burns et al. (2005) did some work on practical changes for the person with dementia which more closely resembles cognitive-behavioural therapy. Sinason (1995) attempted to make interpretations about the content of her client's narrative, but without any feedback from the person with dementia as to whether these are accurate, it is hard to assess if the interpretations were useful. Kitwood and Bredin (1992) argue that the person with dementia is often transformed with human contact and attention, so it is feasible that any benefits found were a result of having someone show warmth and empathy. Consequently from this research it is not possible to conclude whether it was psychodynamic therapy per se that benefited the person with dementia, or the therapeutic relationship.

6.4.2 Implications for Counselling Psychology

Although the literature does not conclude if psychodynamic therapy is beneficial, the research does suggest that people with dementia can respond emotionally in therapy which supports the use of formal counselling methods for people with dementia. In addition, the literature has highlighted some of the practical issues when conducting psychodynamic therapy for people with dementia, which is useful for informing Counselling Psychologists who do apply this technique. For example therapists have cited conducting therapy within the home, creating consistency, being flexible about the use of materials and matching the pace of the person with dementia is important when providing therapy for people with dementia (Hausman, 1992). Also all therapists used a non-confrontational technique and did not enforce the clients to gain insight into their illness. None of the studies mentioned any anxiety responses as a result of insight, as predicted by Cheston (1998), although it is also not clear from the reports how much insight the clients were able to gain. In addition, the importance of being aware of countertransference was demonstrated by Greenwood and Loewenthal (1998).

It is unclear from the case studies presented if the psychodynamic interpretations were helpful to the individuals. Sinason (1995) in particular make quite a significant leap between what the person was saying and what she thought they might be implying. However without feedback from the person with dementia it is not clear if she was correct in her hypotheses. Furthermore, given the impaired cognitive abilities of the person with dementia, it is probable that the individual makes mistakes in their vocabulary. Therefore to assume that the person with dementia is always trying to reveal something about their internal psychological processes might be quite extreme. The studies have shown that above all techniques, the most important aspect of therapy for people with dementia is the therapeutic relationship. Therefore it is appropriate to focus first and foremost on building a rapport with the person with dementia, with any interpretations coming secondary to this primary goal. Furthermore, it might be more suitable to make interpretations that are not too far removed from what the person is communicating given that the person with dementia may be unable to comment on the therapist's accuracy.

6.4.3 Future research

It is clear that there needs to be more research investigating the benefits of psychodynamic therapy in people with dementia. Future research should aim to be more transparent about the therapeutic practice in order to facilitate an evaluation of the psychodynamic model compared to a supportive relationship. Also future studies should consider which stage of dementia psychodynamic therapy is beneficial as it may be useful to change the therapeutic approach as the dementia progresses. Furthermore, supplementing the findings with ethnographic methods, such as observation would also be useful in evaluating the efficacy of this approach.

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