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ACTIVITIES AS RESOURCES WHEN LIVING WITH ADVANCED CANCER

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ABSTRACT

The overall aim of this thesis was to increase knowledge about how people with advanced cancer experience their engagement in activities and how such activities may be useful when living with life-threatening illness. This is explored with regard to creative activities in palliative occupational therapy and to self-chosen activities in everyday life.

Given that improved treatment allows people with advanced cancer to live increasingly longer periods of time, it becomes important to support them in such circumstances. Gaining insight into the potential and the challenges of engagement in activities from the perspective of people with life-threatening illness may generate knowledge that can complement theoretical and practical foundations for the use of activities in therapeutic intervention and everyday life.

The thesis includes four studies. In **Study I** the aim was to discover and characterize components of engagement in creative activity as occupational therapy for elderly people dealing with life-threatening illness from the perspective of clients and therapists (n = 15). This study was based on qualitative interviews analyzed using a constant comparative method. **Study II** aimed to investigate the meanings that people with advanced cancer ascribed to engaging in creative activity in palliative occupational therapy (n = 8). The data from qualitative interviews were analyzed using a phenomenological method. In **Study III** the aim was to describe and explore the daily activities of people with advanced cancer in relation to time, location, social interaction and experience (n = 45). The data were collected using semi-structured diaries and qualitative interviews according to the Time Geographical Method. These data were analyzed using a constant comparative method. **Study IV** aimed to explore and understand how people with advanced cancer create meaning and handle everyday life through activity (n = 7). The data collection was based on a combination of qualitative interviews and participant observation. In this study an interpretive narrative approach was used for the analysis.

The findings in **Study I** identified how clients and therapists contributed jointly in constructing a generous environment supporting engagement in activities. The findings suggested that engagement in creative activity enabled clients to create connections of past experiences with their present situation and connections reaching into a possible future. In **Study II** engagement in creative activities was found to ease living in proximity to death and to provide opportunities for creating new ways of living. This entailed ongoing processes for the participants, which involved confronting the consequences of advanced cancer, experimenting with ways to handle current challenges and acknowledging personal resources. **Study III** identified that the participants with advanced cancer spent most of their time at home. Their daily lives consisted primarily of self-care and leisure activities with limited social engagement. Establishing and maintaining rhythms of routine and change was found to be significant for the participants' sense of satisfaction with daily life. The results of **Study IV** showed how the participants fashioned stories through daily activity that were useful to them in handling everyday life with advanced cancer. These narratives illustrated the challenges faced by the participants' in creating desired stories in negotiation with their socio-cultural environment. Activities were identified as an arena for exploring contrasting feelings of health and severe illness and, in addition, for providing a familiar framework stimulating agency and life-confirming experiences.

Taken together the findings identified various ways in which engagement in activities may provide opportunities to explore and work through consequences of advanced cancer. Engagement in activity was identified as stimulating the discovery of individual and socio-cultural resources that the affected person could draw upon in daily life by taking agency, transcending grief and experiencing enrichment and completion in the face of impending death. These studies may contribute to the development of palliative care and to the support of people with advanced cancer as they explore ways to engage and use activities in the remainder of their lives.

Key words: creative activity, engagement, advanced cancer, palliative OT, experiences of meaning

LIST OF PUBLICATIONS

This doctoral thesis is based on the following four articles, which are referred to in the text by their respective Roman numerals:

- I. **la Cour, K.**, Josephsson S. & Luborsky M. (2005). Creating connections to life during life-threatening illness: Creative activity experienced by elderly people and occupational therapists. *Scandinavian Journal of Occupational Therapy*, 12 (3):98-109.

- II. **la Cour, K.**, Josephsson S., Tishelman C. & Nygård L. (2007). Experiences of engagement in creative activity at a palliative care facility. *Palliative & Supportive Care*, 5,241-250.

- III. **la Cour, K.**, Nordell K., & Josephsson S. Everyday life of people with advanced cancer: Activity, time, location & experience. Submitted.

- IV. **la Cour, K.**, Johannessen H., & Josephsson S. Activity and meaning-making in everyday life of people with advanced cancer. Submitted.

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INTRODUCTION

This thesis focuses on how people with life threatening-illness, in particular advanced cancer, experience and use their engagement in activities when facing limited survival time. Participants' subjective experiences of engagement in activities are explored in the context of palliative occupational therapy (OT) and everyday life in general within the context of home.

Living with advanced cancer, and the knowledge that cure can no longer be expected, has been described as a very diverse and difficult experience that may significantly impact on the everyday life of the individual involved with respect to an array of psychological, physical, social and existential issues (Breitbart, 2002; Cooper, 2007; Grønvold, 2006). Furthermore, reassuring people facing life-threatening illness that there is always something to do even when cure is no longer possible has been stated as being of the utmost importance (Strang, 2002). For such situations, in which meaning and new forms of living everyday life have to be recreated, activity has been recommended as a valuable tool (Lyons, Orozovic, Davis & Newman, 2002; Svidén & Borell, 1998; Svidén, Tham & Borell, 2004). Consequently, it is important to assemble knowledge about activities, about ways in which engagement in activities is experienced and about how activities might be useful for people with advanced cancer. For example, how activities may be useful for handling challenges of everyday living in creating meaning and content in the remainder of those people's lives.

In this thesis, activities are considered as anything that the person engages in during the day, for example making food, practical work in the garden, various forms of creative activity and social interaction with family and friends. Such activities represent what everyday life consists of and what most people do on a daily basis, including people dealing with advanced cancer. Activities can be seen as providing an arena for people with advanced cancer to enact, explore and handle their current situation. Hence,

understanding how engagement in activities is experienced by people with advanced cancer may contribute to support those people in their use of and engagement in activities in everyday life under their given circumstances. However, at present only limited research has been conducted about engagement in activity from the perspective of individuals with advanced cancer.

This thesis is based on four studies, two conducted in Sweden and two conducted in Denmark, each of which explores different aspects of engagement in activity. The sections that follow are written to provide a framework for these studies.

The background presents conditions of living with advanced cancer in Scandinavian countries, definitions of advanced cancer and its consequences, followed by a summary of existing research on activities in relation to people with advanced cancer. Thereafter, definitions of concepts, that are central for the studies, follows. The occupational perspective, which reflects my disciplinary background and has influenced how I have generated and worked with the data, is then presented. Furthermore, the background addresses recommendations for health care services to people with advanced cancer in general palliative care and palliative occupational therapy (OT). Then the background addresses existing research on activities in relation to people with advanced cancer. After the background, the aims of the studies and the summary of the findings are presented. Finally, the findings and methodological considerations are discussed in general, across all four studies, generating reflections on implications for clinical practice and future research.

BACKGROUND

CANCER, LIFE-THREATENING ILLNESS AND ADVANCED CANCER

The number of people who get cancer is increasing worldwide. The World Health Organisation estimates that more than 15 million people globally will be diagnosed

with cancer every year by 2020, and that in Europe 1,7 million people will die from cancer each year (The World Health Organisation [WHO], 2008). The incidence of cancer increases with age and in both Sweden and Denmark cancer is the most common cause of death for people over 65 years of age (Kræftens Bekæmpelse, 2007; The Swedish National Board of Health and Welfare, 2007). As new treatments are developed, the number of people with advanced cancer is growing steadily, and these people live for longer periods (Higginson & Costantini, 2008). Increasing numbers of people are, therefore, facing extended periods living with advanced cancer.

The term cancer is used generically for approximately 200 different diseases (Cancerfonden, 2005), and WHO (2002) identify cancers as life-threatening illnesses. A life-threatening illness is one that presents a very real risk of causing death and implies limited survival time (WHO, 2002). In this thesis, the term 'life-threatening illness' is used interchangeably with the term 'advanced cancer'.

Advanced cancer can be defined as 'cancer that has recurred and/or spread to vital organs in the body' (National Comprehensive Cancer Network [NCCN], 2003).

However, this definition does not include those cases where, a cancer is advanced as cure is no longer expected, although the cancer has not spread. In this thesis, advanced cancer is therefore considered as advanced, when cure is no longer expected and survival time is limited.

CONSEQUENCES OF ADVANCED CANCER

Having advanced cancer influences the individuals' life situation extensively and is characterized by ongoing losses and changes that not only affect the individual, but also their family, relatives and other people close to the patient (Breitbart, 2002; Tishelman & Emami, 2004). These losses are closely related to the disease and to the side-effects of treatment (Kopp, 1997; Zachariae & Mehlsen, 2004). For example, depending on the

type of cancer, the person may experience varying degrees of bodily deterioration (Cooper, 2007; Lyons, Orozovic, Davis & Newman, 2002). Cheville (2001) highlights the fact that patients' fear of impending death is often eclipsed by concern over functional decline and uncontrolled symptoms. Furthermore, Lindquist, Widmark & Rasmussen (2006) identified that, for those living with incurable cancer, bodily problems such as deterioration and impaired functionality were given meaning by patients' perceptions of living in a cyclic movement of losing and reclaiming wellness. The most typical physical problems for people with advanced cancer are the pain, fatigue and side-effects of medical treatment along with psychological problems such as feelings of anxiety and depression (Zachariae & Mehlsen, 2004). Furthermore, many lose their work, their social roles and their relationships. The loss of bodily functions causes a decreasing capacity to carry out the basic activities of daily life (Cheville, 2001; Jacobsen, Jørgensen & Jørgensen, 1998). In addition Olsen, Krawchuk and Quddusi (2007) identified how individuals with advanced cancer may be motivated to do things but lack the energy to carry them out.

Furthermore, an advanced cancer implies that the individual is confronted with the fact that cure is no longer expected. This may involve the individual facing existential concerns in that life is moving towards its end, which implies living with an awareness of impending death (Davidsen-Nielsen, 1995; Hansen, S.R., 2003; Kübler-Ross, 1969/1995). Therefore the diagnosis of incurable cancer can elicit strong emotional reactions, exacerbated by a discourse of death associated with fear and uncertainty in Western society and by the stigma ascribed to cancer (McKechnie, & MacLeod, 2007; Sonntag, 1991; Tritter & Calnan, 2002). In addition, Feigenberg (1976) describes the death process as a phase in life marked by contrasting emotions relating to the present, the past and the future, emotions constantly revaluated and distorted as, for example, the future appears non-existing and the present is dominated by fear.

A model commonly used (Hansen S.R., 2003; Hagelin, 2008) for comprehending the experiences of dying was proposed by Kübler-Ross (1969/1995), who identified five stages that may be experienced in the dying process. The first stage is denial and isolation, which is common among almost all patients, not only at the beginning of disease, but also later on. The second and third stage involves anger and bargaining as the individual wishes to live longer. The fourth stage is dominated by depression, often seen when the person can no longer deny the conditions and anger is substituted by feelings of loss. The final fifth stage is acceptance, when the patient has sufficient time and is no longer depressed or angry with 'destiny' (Kübler-Ross, 1969/95, p.115).

However, Levine has argued that there are no stages but only the 'incessant changes of the mind' (1982, p. 234). Levine suggests that the stages of dying are constantly changing in the process of an ordinary day and in the face of reality. Furthermore he proposes that the stages are parallel to the stages of spiritual growth. In this thesis the stages proposed by Kübler-Ross are accepted as helpful for understanding psychological aspects of living with advanced cancer and, with Levine's arguments in mind, are not seen as distinct entities but as ongoing processes of everyday life.

Based on a study of suffering of patients in a palliative care unit, S.R. Hansen. (2003) focuses on a somewhat different aspect of the consequences of cancer. She suggests a typology of the suffering experienced by people with incurable cancer. This is relevant for exploring the potential of engagement in activities for people with advanced cancer as it helps to understand the conditions and challenges of living under such circumstances (Hansen, S.R. 2003). Living with the awareness of being incurably ill – which includes losing the hope for cure – and being dependent on professionals are among the main features of suffering that S.R. Hansen identifies. Others are: fighting for acknowledgement, protecting oneself from realities, and experiences of powerlessness. In addition, the individual has to adjust to the unpredictability of illness

and fear of the future, exacerbated by increasing pain, while simultaneously struggling to maintain or regain physical strength and independence. Furthermore, the suffering of people with advanced cancer may include fighting for meaningful and life-confirming activities and facing limitations and loss of their previous life.

Several studies have pointed out that cancer disrupts the continuity of ordinary life and the experience and use of time (Breaden, 1997; Crossly, 2003; Rasmussen, 1998; Raunkiær, 2007). In regard to the use of time, Rasmussen and Elverdam (2007) highlight the fact that the confrontation with death made many participants reorganize their life and prioritize how they would spend the time remaining to them. In another study (Rasmussen & Elverdam, 2008, in press) suggest that the natural structure and order of daily living, which had always been taken for granted and which had, for example, been provided by work before the onset of cancer, had disappeared. In a parallel vein Lyons et. al. (2002) point out that people with life-threatening illness are likely to experience progressive reduction of activities as they become ill, which in turn may impact on the individual's perceived health and well-being. Similar consequences of cancer are identified by Vrkljan and Miller-Polgar (2001), in that they suggest that life-threatening illness challenges the individual's ability to engage in meaningful occupation as a consequence of decreasing choice and control in everyday occupations. Although the consequences of advanced cancer has profound and widespread effects on the life situation of the individual, including on their ability to engage in activity, little attention has been directed towards the subjective experiences of engagement in activity or on ways in which activity may be useful in the remainder of these people's lives.

ACTIVITIES AND CREATIVE ACTIVITY

This thesis focuses on activities of everyday living and creative activities in palliative OT. Therefore definitions of the terms activities and creative activity are presented in the following.

Activities

The concept of activity used in this thesis is understood parallel to occupation, defined as the culturally and personally meaningful activities in which individuals engage on a daily basis or at various times throughout their lives (Jackson, 1996). The understanding of occupation and activity takes its point of departure in the definition made by Law and co-workers who proposed: *Occupation refers to groups of activities and tasks of everyday life, named organized, and given value and meaning by individuals and a culture. Occupation is everything people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure), and contributing to the social and economic fabric of their communities (productivity)* (Law, Poletajko, Baptiste & Townsend, 2002, p. 34). This definition suggests a broad understanding of occupation by capturing groups of activities. Furthermore, this definition recognizes that activities are organized and given value both by individuals and by culture. The term 'activity' is commonly used in literature to refer to activities of everyday living. Therefore, in this thesis, the term activity will also be used when referring to such activities.

The focus on activities in this thesis is particularly concerned with *engagement* in activities of people with advanced cancer. According to Yerxa (1998) active engagement includes an act of will and an experience of engagement which connotes that the concept is characterized by subjectivity and intention. This definition is used in this thesis to emphasize engagement as a form of personal investment, through which

the individual can make active use of activities to express their own ideas and interact in various socio-cultural contexts.

Creative activity

A broad range of definitions of creativity have been proposed (Creek 2002; Csikszentmihalyi, 1997; Kjørup, 2000; May, 1994). Their most common characteristics when defining creativity pertain to being innovative and giving life to ideas in the making of something new. From an occupational perspective Schmidt (2004, p. 6) defines creativity as *'the capacity to think and act in original ways, to be inventive, to be imaginative and to find new and original solutions to needs, problems and forms of expression. It can be used in all activities'*. In line with her reasoning, creative activity is not only associated with a specific kind of activity but is rather a capacity that can be expressed and enacted through an array of activities. This can be achieved, for example, through practical work, with crafts, or in any activity employed to create meaning in everyday life and to handle daily challenges. Thus, in this thesis creative activity is understood as a capacity explored in regard to engagement in activities.

AN OCCUPATIONAL PERSPECTIVE AND POTENTIALS OF ACTIVITY

This thesis builds upon an occupational perspective which focuses on activity as an aspect of human existence. This perspective rests upon basic assumptions of occupational therapy that state, that activity is an integral part of human life as an explicit human phenomenon (Reilly, 1974). This perspective is developed by the ideas of occupational science, an evolving science of occupation first formulated as 'the study of the human as an occupational being', one of whose premises is that people have the need for and capacity to engage in and orchestrate daily occupation in their environment over their life-span (Yerxa et al., 1989 p. 9). These ideas were extended by

Chapparo & Ranka (1997), who proposed that an active human being presents aspects of ideation and actualization of engagement in activity. Thus an occupational perspective relates to engagement, which is being explored in this thesis as an aspect of activity (Zemke, 2004).

Furthermore, the occupational perspective proposes that the experience of meaning, wellbeing and health is closely linked to engagement in activity in everyday life (Yerxa et al., 1989; Wilcock, 2006). From an occupational perspective, meaning can be seen as derived from engagement in activities (Jonsson & Josephsson, 2004), and in that regard narratives have been identified as resources to understanding how meaning-making may take place through activities (Barber, 2004; Josephsson, Asaba, Jonsson & Alsaker, 2006; Molineux & Whiteford, 2005). To put it briefly, a narrative approach emphasizes the notion of emplotment as being central for human meaning-making. Emplotment is constituted through the linking of materials, such as events and activities, into coherent wholes that facilitate meaning of past and present experiences and point towards a potential future (Ricoeur, 1984). Furthermore, Meyer (1922/1977) suggests that people influence their own health through creating and preserving a balance of bodily and temporal activities such as play, work and rest. Such a balance of activity is, according to Zemke (2004), closely linked to the concept of temporality. Temporality involves the experience of time shaped by engagement in occupation (Zemke, 2004; Zemke & Clark, 1996). An occupational focus on temporality is, therefore, used to address participants' experience of time as shaped by engagement in occupations. It is relevant to include these ideas when trying to understand the experiences of engagement in activity of people with advanced cancer.

In addition to Meyer's ideas about health (1922/1977), Wilcock (1998; 2006) establishes the importance of attending to doing, being and becoming in terms of health. She complements to understandings of health as closely linked to people's

direct experiences of doing and being, ‘through the essential interests that drive individuals’ (Wilcock, 2006, p.115), along with processes of becoming in aiming towards personal development and well-being. To sum up, the ideas of Meyer (1922/1977) and Wilcock (2006) suggest that experience of health is related to a balance of activity in ongoing processes of doing, being and becoming, which is in line with the salutogenic orientation to health as proposed by Antonovsky (1987). In short, the occupational perspective emphasizes that understanding of human activity in time and space is closely related to experiences of meaning and health. Although the occupational perspective emphasizes this relationship between engagement in activity and experience of meaning and health, there is limited empirical research that more specifically explores how this relationship takes place in the lives of people with advanced cancer.

PALLIATIVE CARE AND PALLIATIVE OCCUPATIONAL THERAPY

When cure is no longer expected for people with advanced cancer, palliative care is a form of health care that is commonly offered. Palliative care is rooted in the hospice movement founded by Dame Cicely Saunders in the early 1960’s in Great Britain (Saunders, 1998; Abel, 1986) and based on the central idea that death is part of life and that the experience of dying should be meaningful. Emphasis was placed, for example, on the idea that patients should be supported in opportunities for physical as well as mental activity to preserve self-control and independence as much as possible (Saunders, 1998).

According to WHO (2002), palliative care seeks to improve the quality of life of patients and families who face life-threatening illness by providing pain and symptom relief and by offering spiritual and psychological support from diagnosis to the end of life and through bereavement. Based on this definition, palliative care does not only

apply to people in the later stages of illness but can be relevant throughout the disease trajectory. It should be noted, however, that palliative care is more dominant as an intervention when cure cannot be expected (Cancerfonden, 2005). Furthermore, palliative cancer care is described as including a prolonged early phase and a shorter late phase that might last days, weeks or some months (Socialdepartementet [SOU], 2001). The European Association for Palliative Care (European Association for Palliative Care [EAPC], 2002) has extended the understanding of palliative care by stating that:

Palliative care is the active, total care of the patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of social, psychological and spiritual problems is paramount. Palliative care is interdisciplinary in its approach and encompasses the patient, the family and the community in its scope. In a sense, palliative care is to offer the most basic concept of care – that of providing for the needs of the patient wherever he or she is cared for, either at home or in the hospital. Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death. It sets out to preserve the best possible quality of life until death.

The EAPC definition specifies that palliative care is called for when curative treatment is no longer possible. Furthermore EAPC emphasize an interdisciplinary approach in the definition.

Generally, palliative care for people with advanced cancer is organized and provided in a variety of ways and officially divided into *basic* and *specialized* palliative care. Basic palliative care is provided at hospitals and as community-based services, for example by the family doctor or home-care nurse. Specialized palliative care is provided by hospices and hospitals, through in-patient palliative care units and palliative care teams,

for example, providing services in the home (Sundhedsstyrelsen, 1999; The Swedish National Board of Health and Welfare, 2007). Due to the decentralized health care systems in both Sweden and Denmark the provision of palliative care is developed to varying degrees in the different regions of each country (The Swedish National Board of Health and Welfare, 2007; Sundhedsstyrelsen, 2007).

Interdisciplinary approaches in palliative care mean that palliative occupational therapy can be offered. Palliative occupational therapy (OT) is based on a holistic client-centred approach, which is constantly reassessed according to the needs of the individuals and their carers (Cooper, 2007). The role of the occupational therapist when working with people with advanced cancer is to value their remaining life, to support them in living in the present by optimizing independence and quality of life and to assist in the preparation for approaching death within the ethical guidelines and the professional code of conduct (Cooper, 2007; Penfold, 1996; Trump, Zahoransky & Siebert, 2005). Palliative OT compliments the other services/therapies through its focus on activity that includes enabling individuals to engage and perform activities and occupational roles of daily living that are perceived by the individual and the caregivers to be important, given the limitations of time and of physical ability (Kealey & MacIntyre, 2005; Lloyd, 1989). Palliative OT is a service that is commonly integrated into palliative care services in countries like the United Kingdom (Cooper 2007), USA (Pizzi & Briggs 2004), Canada (Vrkljan & Miler-Polgar, 2001), Australia (Lyons et al., 2002; Taylor & Currow, 2003) and Sweden (Dahlström & Svedin, 1997). In Denmark OT is not integrated in palliative care and currently only few OT's provide services for people with advanced cancer (Hjelmroth, 2007).

EXISTING RESEARCH ON ACTIVITIES IN RELATION TO PEOPLE WITH ADVANCED CANCER

Most people who have advanced cancer experience radical change and disruption to their everyday life (Lyons et al., 2002; Raunkjær, 2007; Svidén, in press). People with advanced cancer are confronted with existential issues, as cure of their illness is no longer expected, and the extent to which they can undertake the activities they used to manage prior to illness is constantly decreasing (Kealey & McIntyre, 2005) This situation demands that individuals must rework prior understandings of the self and develop new ways to create meaning and content in the life remaining to them. It is in such situations that engagement in activity may be relevant (Lyons et al., 2002; Vrkljan & Miller-Polgar, 2001). For example, engagement in creative activities, like arts & crafts, have been recognized to have a wide range of benefits, such as providing relief from worries, increased enjoyment, improved sense of self-identity and enabling experiences of health and well-being (Bailey, 1997; Connell, 2001; Heywood, 2003; Richardson, 2001). A study by Luzzato et al. (2003) identified that art therapy can provide a communication tool for cancer patients. This study addressed the way symbolic expressions were used in a specific art therapy programme as a means for dealing with the physical and emotional pain associated with cancer. Along similar lines Ponto et al. (2003) identified how the process of creating art can be used therapeutically to help patients express their thoughts and feelings. A study by Heywood (2003) confirmed the positive benefits of art therapy as supportive in times of emotional distress, providing a safe place in which to express different kinds of feelings and giving an opportunity to play an active rather than a passive role.

Together these studies identify significant enriching effects of participating in art therapy as a valuable means for people with cancer. However, these studies tend to focus on the 'outcome' of participating in art therapy in relation to; for example,

distressing symptoms of cancer such as pain (Luzzato, 2003). To further the understanding of engagement in activities such as those provided in art therapy, there is a need to explore the underlying mechanisms of such activity in terms of how it takes place and is experienced by people with cancer.

Other studies explore participation in palliative care programmes and day care centres on a more general level, without attending to specific activities. For example, Lawton (2000) identified the fact that people dying of cancer experienced day-care as a safe retreat that provided a space for sustaining the self. Lawton identified day-care as an 'alternative reality' to life outside day-care. Furthermore, she proposed that the organization of day-care around stable routines serves as a locus of continuity in the patient's lives. Lawton's study also devotes attention to the organization of time and how time-use may support people living with advanced cancer. Several studies have identified how people with cancer experience and prioritize time in new ways (Rasmussen & Elverdam, 2007; Raunkiær 2007). These studies raise questions as regards to the way time is experienced and managed through engagement in activity. The studies presented above on art therapy and palliative care focus on activities that people with cancer can attend in institutional settings. However, today increasing numbers of people with advanced cancer choose to live at home (Lock & Higginson, 2005) and thus spend more time at home in their last period of life. This makes it relevant not only to attend to the activities of people with advanced cancer in contexts of palliative care but also in other contexts of everyday living.

A substantial study by Grønvold, Pedersen, Jensen, Faber and Johnsen (2006) found that many patients requested help in daily living with symptoms of cancer.

Furthermore, Grønvold et al. (2006) stress that knowledge on the everyday needs of people with advanced cancer is limited. Raunkiær (2007) also pointed out that studies

of people who are dying from cancer rarely focus on the conditions of everyday life from the perspective of the dying. One way to understand the conditions and needs of everyday life of people with advanced cancer is to assemble specific knowledge about the activities that comprise the daily living of these people. Furthermore, if we are to support people in living with advanced cancer, it is necessary to gain in-depth knowledge about how these people experience their engagement in their daily activities.

From an occupational perspective, a study by Svidén, Tham and Borell (in press) showed how people with incurable cancer strive to remain involved and to be active in everyday life and how this can be a powerful source of experiences of pleasure and competence. This study supports an understanding of activity as a potential therapeutic tool and a resource for people with advanced cancer. In addition, the study found that participants can continue active involvement by lowering their expectations of their performance of the activities they engage in. By extension it is of considerable interest to gain an insight into how activity 'works' and may be useful in achieving experiences such as pleasure and competence, when living with advanced cancer.

In summary, little is yet known about underlying mechanisms of engagement in activity, such as how the actual doing may be a resource for people in dealing with an advanced cancer and the wealth of meanings and implications that experiences of such activity may have. In other words, it is not sufficient to document the fact that engagement in activity has positive effects. We also need to know, in much more detail, how enriching experiences and positive effects such as pleasure and competence come about so that the potential of activity can be utilized. Furthermore, the WHO (2004) emphasizes that palliative care services should offer a support system to help patients live as actively as possible until death and enhance the quality of life and so possibly

having a positive influence on the course of illness. It is, then, highly relevant to the development of palliative care that attention be paid to how an active life can be supported, and in what ways activity is useful for such purposes.

RESEARCH AIMS

The overall aim of this thesis was to enhance knowledge about how people with advanced cancer experience their engagement in activities and how such activities may be useful when living with life-threatening illness. This is explored with regard to creative activities in palliative occupational therapy and to self-chosen activities in everyday life.

The specific aims for each of the four studies were:

- To discover and characterize components of engagement in creative activity as occupational therapy for elderly people dealing with life-threatening illness from the perspective of clients and therapists.
- To investigate the meanings that people with advanced cancer ascribe to engaging in creative activity in palliative occupational therapy.
- To describe and explore the everyday activities of people with advanced cancer in relation to time, location, social engagement and experience.
- To explore and understand how people with advanced cancer create meaning and handle everyday life through activity.

METHODS

The conduct of research is usually governed by the nature of knowledge it seeks to produce (Sandberg, 1995). In this thesis the research interest was to explore and extend knowledge about engagement in activities of people with advanced cancer in various contexts. Therefore a qualitative methodology was relevant for the studies in this thesis. Qualitative inquiry and research methodology can be understood as generic terms for methods that seek in-depth description and understanding of the qualities of given phenomena (Gubrium & Holstein, 1997). Qualitative methods usually address research questions relating to what, how and why (Maxwell, 1996). The particular focus of the current studies was to understand the participants' experiences of engagement in the activities they were involved in, based on their accounts and actions in their everyday lives in context of palliative OT and home. Furthermore, the intention with the studies was to develop knowledge about what activities the participants with advanced cancer engage in, and how these activities are made use of through processes of engagement, based on the participants' subjective experience.

Engagement in activity is a complex phenomenon and in order to explore various aspects of engagement in activities of people with advanced cancer, each of the studies in this thesis was designed using different qualitative methods. To explain how the different qualitative methods complement knowledge of engagement in activity, theoretical assumptions for the methods used in the four studies are described below, and these are followed by a description of the specific methods.

THEORETICAL ASSUMPTIONS FOR THE RESEARCH METHODS

The research methods used in the studies in this thesis draw on assumptions grounded in; social interactionism (Schreiber & Stern, 2001; Strauss & Corbin, 1998),

phenomenology (Husserl, 1900/1970; Karlsson, 1995) and narrative theory (Mattingly, 1998; Polkinghorne, 1988; Ricoeur 1985). These are briefly presented below.

The methodological approach in Study I and III is rooted in symbolic interactionism, which builds on the assumption that human meanings are negotiated and developed through social interaction (Schreiber & Stern, 2001; Strauss & Corbin, 1998).

Therefore symbolic interactionism allows for the exploration of experience and meaning as constructions that people create through interaction with others. This approach was used in Study I to explore engagement in activity from the perspectives of clients and therapists in palliative occupational therapy. In that study symbolic interactionism was drawn upon to shed light on the participants' experiences of engagement in activities and interaction with one another (Heath & Cowley, 2003; Schreiber & Stern, 2001). Further, symbolic interactionism builds on the assumption that the relationship between activity and meaning is a dynamic process through which action and interaction influence contexts and lead to the construction of new and alternative meanings and activities (Schreiber & Stern, 2001). Study III was based on these ideas, as it focused on exploring relationships between the participants' experiences of activity and contextual dimensions such as time, location and social interaction. Thus a methodological approach based on symbolic interactionism contributed to this thesis by supporting the exploration of processes whereby people with advanced cancer construct and reconstruct their lives and interact within various contexts.

The methodological approach in Study II was based on phenomenological traditions (Husserl, 1900/1970; Karlsson 1995) seeking to understand the lived experience of engagement in activity. The notion of lived experience can be traced back to the phenomenological idea of the life-world as developed by Husserl (1900/1970) and

further developed by Heidegger (1926/1995) and Merleau-Ponty (1945/2002). The idea of life-world expresses the inseparable relationship between subject and world, stipulating that person and world are related through the persons' lived experience of the world. An approach based in phenomenology, therefore, offers insight into subjective experiences of engagement in activity as the participants 'live' them in the context of palliative occupational therapy. This approach was useful in Study II to explore the meaning of engagement in activity and to allow a focus on the perspective of the participants.

In Study IV the methodological approach was based on using narrative theory to explore and understand meaning-making through the participants' talk about and enactment of activity. Narrative theory proposes that individuals make meaning of their experiences in an ongoing emplotment of those experiences into coherent wholes (Ricoeur, 1985, Mattingly, 1998). This approach is useful in suggesting a way of exploring the relationships between experience and meaning-making, which is in line with the aim of Study IV, namely to explore and understand how people with advanced cancer create meaning and handle everyday life through activity. Furthermore, there is the suggestion (Ricoeur, 1985, Mattingly, 1998) that narrative emplotment is created as stories that are told as well as stories that are enacted in communication with the socio-cultural environment. In this way narrative provides a theoretical tool to link and understand aspects of meaning-making through engagement in activity as constructed in given contexts of living. To elaborate the understanding of people's construction of stories in the context of everyday life, the proposal by Goffman (1971) that people perform stories in striving to control their impressions on others and thus gain social approval and self-enhancement, was used for the analysis. Goffman's proposal (1971) links activity to stories as performed expressions of meaning and was applied in Study

IV to explore how participants performed and presented themselves through the stories they told and enacted in daily activity with possible socio-cultural implications.

PARTICIPANTS AND SAMPLING

The participants in the studies in this thesis were people with life-threatening illness, primarily advanced cancer. There was one stroke survivor who attended palliative care in Study I. An overview of participants, methods for collection and analysis of data and study contexts is presented in table 1.

Table 1

	Study I	Study II	Study III	Study IV
Participants	n = 15, 8 clients, 4 male and 4 female 7 female therapists	n = 8 7 female and 1 male	n = 45 23 female and 22 male	n = 7 5 female and 2 male
Age range	60 - 89	41 - 74	39 - 80	40 - 67
Research approach	Qualitative, explorative	Qualitative, phenomenological	Qualitative, explorative	Qualitative, narrative/interpretive
Data collection	Semi- structured interviews	Semi-structured interviews	Time Geographical Method including diaries and qualitative interviews	Qualitative interviews and participant- observations
Analysis	Constant comparative method	Empirical Phenomenological Psychological method	Time-use descriptions and constant comparative method	Interpretation using narrative theory and relevant literature
Context	Palliative occupational therapy with creative activities. In Sweden	Palliative occupational therapy with creative activities. In Sweden	An oncology out-patient unit and participants' homes. In Denmark	An oncology out- patient unit and participants' homes. In Denmark

Study I

In Study I a purposive sample (Luborsky & Rubinstein, 1995) of 15 people, 8 clients and 7 therapists, was recruited over a period of 6 months from a hospital and nursing home specializing in rehabilitation, palliative, and geriatric care. The inclusion criteria were that clients should be over 60 years of age, participate in creative activity in palliative occupational therapy (OT) and be able to participate in interviews. Four male and four female aged 60-89 agreed to participate. Two of the males had myeloma, one had kidney cancer and one was a stroke survivor. Three of the females were diagnosed with breast cancer and one of them had lung cancer. Criteria for inclusion of therapists were that they should use creative activities as intervention with the clients. Seven therapists participated. They were all females aged 30 -51 with between 1 and 10 years experience of using creative activities in OT. All participants, both clients and therapists, were involved on various occasions in similar kinds of creative activities in OT. Examples of the creative activities were pottery, different kinds of painting, woodwork and gardening.

Study II

In Study II eight participants who had attended creative activity as clients at the Occupational Therapy Services (OTS) for between one and five years, and who were interested in participating in the study, were recruited by the occupational therapists at the OTS. Four of the participants had previously been interviewed about creative activities in study I. Four additional participants were recruited to achieve more variation and depth in the data. The participants ranged in age from 41 to 74 years and all had advanced cancer. Seven of the participants were females with primary breast cancer and one was a male with multiple myeloma. Six participants had experience with creative activity in the form of crafts prior to OTS. Two of the females were

occupied primarily with sewing and knitting at the OTS while the others participated in a range of activities.

Study III

Sixty-four patients were identified as eligible participants for Study III and invited to participate. In total 45 of the patients agreed to participate in the study. Nineteen participants invited did not participate for a number of reasons. Eight of them died, 10 of them reported that they did not have the energy to participate and one did not consider herself relevant for the study. The 45 participants were consecutively sampled from an oncology out-patient unit. The group comprised male and female patients with advanced cancer for which cure was no longer expected and with an age range between 39 and 80 years. Inclusion criteria were that the group should represent the three cancer diagnoses that were most common at the hospital where the study took place (lung cancer, breast cancer and colon cancer) with attention paid to variation in gender and age. Participants who met the sample criteria were invited to participate by a nurse who provided verbal and written information about the study.

From the 45 participants a purposive (Luborsky & Rubinstein, 1995) sub-sample of seven participants was recruited for in-depth qualitative interviews. Inclusion criteria for the sub-sample were: a) variation in the activities that the participants engaged in on a daily basis, b) variation in their social situation such as living alone or co-habiting, c) variation in age, and d) representation of the three cancer diagnosis groups; lung cancer, colon cancer and breast cancer. The seven participants sampled for the interviews were five females and two males between 39 and 67 years of age. Two participants had breast cancer, three had lung cancer and two had colon cancer.

Study IV

The participants in Study IV were the same seven participants who were sampled for in-depth interviews in Study III. The rationale for including them in Study IV was that they had advanced cancers where cure was no longer expected. These participants were contacted by the first author to arrange a time to meet in their home for interview and observation. Further meetings for the purpose of interview and participant observation were arranged individually. In total 12 meetings with the participants took place lasting between one and three hours.

DATA COLLECTION

Interviews

Qualitative interviews (Kvale, 1996) were used as a method for data collection in all four studies. In Study I and II, interviews carried out using a semi-structured approach were the only method for collection of data. A few main questions were developed in order to address the research question of the studies and to provide an initial structure for the interviews. In Study I, the interview questions concerned the participants' experiences of engagement in creative activities in occupational therapy, and all 15 participants were interviewed once, each interview lasting 30-45 minutes. In Study II sixteen interviews were conducted with eight participants with periods of 6 to 10 months between interviews. Frankl (1946/1985) and Polkinghorne (1988) argue that meaning and personal experience are expressed through thoughts, feelings and actions that unfold and change over time. Therefore it was intended, in Study II, to interview the participants twice with an interval between. These interviews were conducted on the premises of the OTS where participants were recruited. One participant died before her second interview could be completed. Six participants were interviewed twice, and one was interviewed three times to see if a third interview would add any extra dimensions to the data. This was, however, not the case.

In Study III and IV the interviews were conducted after the participants had written a diary according to the Time Geographical Method (TGM) (Ellegård and Nordell, 1997). These interviews took their point of departure in an initial reading of the diaries. This is to say that topics that the participants had written about in their diaries formed the basis for questions raised in the interview. For example, one participant had written about her participation in a 'private club' and so she was asked to elaborate on this activity during the interview.

The interviews for Study III and IV were carried out in the participants' homes and focused on their experiences of engagement in activities in daily life. Interviews from all studies were audio-taped and transcribed verbatim.

Time Geographical Method - Diaries

The Time Geographical Method (TGM) that was used in Study III combines the use of diaries and qualitative interviews to collect data about how time is spent in various activities and contexts during the day as recommended by Ellegård and Nordell (1997). Researchers (Erlandsson & Eklund, 2006; Bendixen et al., 2006; Liedberg, Hesselstrand & Henriksson, 2004) have recommended time-use diaries to collect data about how people occupy their time in daily life. They emphasize that time-use diaries are useful for studies of peoples' objective and subjective life contexts as the method includes both registering and interviewing respondents about activity in relation to time, location, social engagement and experience (Nordell, 1994). More specifically the TGM requires the participants to keep a semi-structured diary of the activities they undertake, when they undertake the activities, with whom, where and how they are doing. The latter relates experiences of physical discomfort and state of mind during activities. According to Ellegård and Nordell (1997), the TGM is intended to be used as an action research method whereby participants write diaries that are followed up by interviews and they can use that process to gain insight into

their own ways of life which may facilitate desired changes. In Study III the TGM diary was used to acquire knowledge about the everyday life activities and contexts of people with advanced cancer and was not intended to stimulate individual change. Furthermore, the method was chosen as it was expected to be useful in gaining insight into the daily activities of people with advanced cancer, while subjecting the participants in the study to minimal intrusion in their everyday life. Once the participants had agreed to participate in the study, they were provided with a TGM diary and written information about how to use it. This was either given to them personally at the hospital or sent by regular mail. All participants were contacted by telephone as a way of following up and responding to any questions they might have concerning how to complete the diary. The participants had the diaries for periods varying from two weeks to two months and they were asked to complete their entries for three individual days of their choice.

The TGM diaries were collected over a period of approximately two years.

Observations

Participant observation (Davies, 2001) was chosen as a method for complementing data from Study IV in order to explore the actual conduct of activity and the given context. Participant observation allows activity to be observed as it takes place and makes tacit or implicit meaning embedded in the participants' conduct of activities more comprehensible. Participant observation may range from complete participation to complete observation (Morse & Field, 1996). In Study IV participant observation was conducted on the level of 'observer-as-participant' (Morse & Field, 1996, p 88), which primarily involved observation and minimal participation. The participant observations were used to gain insight into the context of home and the daily life environment of the participants and to explore how certain activities were carried out. For example, the

meetings between researcher and participants naturally became occasions for observing daily activities such as making coffee. Furthermore, in conjunction with interviews participants were encouraged to share and demonstrate how they carried out activities to which they ascribed particular value, such as gardening. This allowed the collection of data on immediate experiences and on reflections in the midst of activity. Field notes were made up of the data from observations. Participant observations were conducted in the homes of seven participants at 12 meetings over a period of eighteen months.

DATA ANALYSIS

Constant comparative method

A constant comparative method of analysis (Strauss & Corbin, 1998) was used both in Study I and III. This method is based in Grounded Theory as developed by Glaser and Strauss (1967/1999) and has its roots in symbolic interactionism (Heath & Cowley, 2003; Schreiber & Stern, 2001). The constant comparative method is useful to compare data from different sources or collected by different methods (Glaser & Strauss, 1967/1999; Schreiber & Stern, 2001). For example, in Study I the constant comparative analysis involved comparison of data from interviews with two groups of participants, clients and therapists. In Study III the constant comparative method was used to compare data collected by two different methods of data collection, diaries and interviews, from a single group of participants. The analysis involved comparing different types of data from the two methods in order to systematically trace out categories and relationships within the data.

The constant comparative method involves a back-and-forth process between analysis and data (Strauss & Corbin, 1998), in order to identify central categories and their relative disposition to one another. This was done in the following series of steps. First, the empirical data from the interviews with each of the clients and therapists in Study I

was read repeatedly to achieve a thorough understanding of their content. A similar procedure was used in Study III for the TGM diaries of individual participants, their time-use graphs and interviews. However, in Study III the data deriving from the TGM diaries were initially organized using a specific software program developed for the TGM (Ellegård & Nordell, 1997). The software program organizes the data from the TGM diaries in various contexts and uses graphs to illustrate time-use patterns showing which activities people undertake (activity context), where (geographical context), with whom (social context) and how they are doing (experiential context). Also included are frequency, number of social contacts and duration of registered activities. These data derived from the diaries were considered 'non-technical literature' as described by Strauss & Corbin (1998) and included as data analyzed by means of constant comparative analysis.

Next the data from individual interviews with clients and therapists in study I and individual diaries, time-use graphs and interviews in Study III were assigned codes based on a line by line reading. Initially the participant's own words were retained but later codes created by the researcher were used.

By identifying and constantly comparing the relationships and patterns of difference and similarity between the different codes, it was possible to build categories of those with familiar features. For example, in Study I the clients and therapists had described experiences of stepping over thresholds. These were, therefore, assembled in a sub-category named *Daring to create*, which described the way in which, by daring to step over their individual thresholds, clients and therapists jointly contributed to establishing a generous environment that facilitated engagement in activity. As an example from Study III, the analysis showed that all participants were in different ways striving to establish rhythms consisting of routines and change which led to the category '*Aspiring towards familiar days through rhythms of routine and change*'.

Finally the categories identified were conceptualized with their characteristics and relative disposition to one another. In Study I a core category and three sub-categories were identified and in Study III three categories were identified. In both Study I and III the initial analysis was conducted independently by the first author. As categories emerged, the co-authors were involved in careful discussion of analysis, including a constant comparison of raw data, codes and categories identified in a back and forth process, to ensure that the findings were well grounded in the empirical data. In addition, the results were subject to peer review by fellow researchers to ensure that the logic leading to the findings was clear.

Empirical phenomenological psychological method

In Study II data were analyzed using the empirical phenomenological psychological method (EPP) (Karlsson, 1995) in order to capture the meaning of the participants' experiences. The original psychological perspective of the EPP method was changed to an occupational perspective on the experiences and meanings of engagement in creative activity. The method aims to describe the meaning structure of a life-world phenomenon, based on the lived experiences of the participants in the study. The phenomenon in Study II was conceived as *the meanings of engaging in creative activity*.

Analysis conducted with the EPP method involves a bracketing of the researcher's theoretical knowledge in order to allow understanding the meaning of the lived experience, as it appears on its own terms (within the perspective taken). For example, in Study II individual interviews were read with an open mind to obtain an understanding without imposing any theory or pre-understandings. More specifically, the interviews in Study II were first read to gain an understanding of both explicit and implicit meanings that imbued the participants' descriptions of their engagement in

activities. Then the data was divided into units of meaning whenever a shift in meaning was identified in the text. These meaning units were then analyzed for implicit meanings in relation to the data as a whole and transformed into a language close to the data to make this explicit and identify themes. These themes were then organized into 'situated structures' (Karlsson, 1995), capturing the meanings of the phenomenon applicable to each participant. The continued analysis was based on the situated structures of all participants, which were compared and interpreted to identify a general structure that described and characterised the meaning of engaging in creative activity. Throughout the analysis the first and third author discussed the interpretations and later the other authors joined the discussions about the characteristics identified to make sure that the most valid interpretation was reached. This means that consistency and fit between characteristics were repeatedly refined to achieve a 'horizontal consistent interpretation' (Karlsson, 1995). In addition the findings were discussed with fellow researchers to ascertain that the logic of interpretation was transparent to others.

Narrative analysis

In Study IV the data were analyzed with an interpretive method based on Ricoeurs (1985) theory of narrative emplotment and with the reasoning on narrative by Polkinghorne (2004) and Mattingly (1998) as additional resources. Ricoeur (1985) identified emplotment as the linking of relations between materials such as events, actors, motives and desires into meaningful configurations, which is useful for understanding processes of meaning-making.

Specifically, the analysis was performed as follows. First a careful reading was carried out of all material from interviews and from participant-observations re-written as full text to get the gist of each participant's stories. Next, significant events

were identified within the stories. Significant events were understood as events that people found were worth telling stories about and which may therefore be considered as particularly meaningful to them (Mattingly, 1998). For example, participants shared that they had been told that there was no cure for their disease, which was identified as a significant turning-point motivating participants to make the best of the remainder of their lives and ‘to say goodbye in a good way’, as they put it. The data were scrutinized to identify narrative structures such as plots within the individual stories (Mattingly, 1998; Polkinghorne, 2004). Here plots were understood as structures within people’s perceptions of relationships between events and choices in daily life (Polkinghorne, 2004). With the structures of a story in mind, storylines around significant events were then constructed (Polkinghorne, 2004). In order to understand the processes underlying activity and meaning construction, the data underwent a process of questioning to identify reasons and motives to explain the actions and circumstances contributing to the storylines.

Questions posed related to issues such as: What stories did the participants share? How were the stories created? For whom were they created? As an example, a narrative of ‘I am healthy although I am sick’ showed how the participants created a story through which they could claim to be both healthy and sick within their situation. This story was identified as featuring both in the verbal accounts of the participants and in their activities, being enacted, for example, as participants continued to perform activities that they associated with being healthy, such as doing chores around the house, despite being in pain. Subsequently, common storylines were identified among the participants’ narratives and reconstructed into a few narratives that conveyed their stories.

After the first author had conducted the narrative analysis of data, these findings were discussed with the co-authors, who then contributed with ideas for continued analysis.

In this part of the analysis references were made to relevant existing literature that could broaden the understanding of the findings. For example, theoretical propositions from Goffman (1971) and Heidegger (1926/1995) were used to illuminate how the different plots identified might serve the participants in living in proximity to death. The final interpretations agreed upon by all authors were finally presented to a group of senior researchers and fellow doctoral students in a peer review.

ETHICAL CONSIDERATIONS

The studies in this dissertation involved people with advanced cancer, who are in a vulnerable life situation, and who might be fragile when participating in research studies (Barracough, 2001; WHO, 2002). A primary issue is, whether it is ethically appropriate to burden people in such a situation with the task of spending their limited time and resources on a research project (Barnett, 2001). Furthermore, whenever questions are asked about the participants lives, whether is it through interviews, diaries or participant observation, they represent an occasion that can initiate reflections upon their life. This may involve emotions that are both enriching and uncomfortable. Consequently, recruiting people with advanced cancer to the research studies in this thesis raised several ethical concerns.

First of all, providing sufficient and comprehensible information about voluntary participation in each research study to the potential participants was difficult, as it was not possible to fully foresee how the information would be received, and whether the individuals, who were contacted, could judge how participation in a given study may influence them and their situation. Therefore care was taken to prepare both the written and verbal information for each study carefully. For example, in Study I the written information to clients was first reviewed by a senior researcher and then by an occupational therapist working on a daily basis with clients who had advanced cancer. The written information to the therapists was also subject to review by experienced researchers before it was distributed to potential participants. In addition, this was followed up by providing the participants with verbal information and the opportunity to raise questions regarding the project. In Study III and IV, which involved the use of diaries, the diaries were reviewed by senior researchers and piloted with people from a local voluntary network organization who had advanced cancer. The participants in all four studies received written and verbal information

about the projects and were given time to consider their participation before giving their verbal consent.

Another dilemma that can occur throughout contact with research participants is that a question about engagement in activity or changes in everyday life may expose problems, regarding some aspect of the disease and its consequences that the person was not aware of. It may thereby cause increased awareness and possible concern or anxiety. Meetings with participants in each of the studies were, therefore, conducted with special attention and care paid to the condition and mood of each individual.

In Study III and IV some of the initial participants explained that writing the diaries and participating in interviews had been useful to them in gaining an insight into aspects of how they approached everyday life. For example, one participant said that the diary had raised his awareness of his own 'intolerance' with himself and this had prompted a change in his attitude towards greater leniency. Similar responses from a number of participants led to the introduction of the procedure to ask all participants about their experience of participating in the project. As a whole, participation in the study seemed to be considered to be enriching by the participants and signified an interest in their situation on the part of the health care system.

In accordance with the ethical principles recommended by the Danish Social Science Research Council (2002), information on the right to withdraw from the studies at any point in time was given to all participants. They were assured that any information given would be treated in confidence and reported anonymously.

Approval of Study I and II was obtained from the ethical committee responsible in Sweden and approval was given for Study III and IV by the Danish Data Protection Agency.

FINDINGS

In **Study I**, the aim was to discover and characterize components of engagement in creative activity as occupational therapy for elderly people, dealing with life-threatening illness, from the perspective of clients and therapists. The findings showed that engagement in creative activity could enable the clients' creation of connections between past experiences and their present situation and everyday life. A generous receptive environment was identified as being a key factor in enabling clients to pursue engagement in creative activity and ongoing life while facing imminent death. A generous environment was found to be established by means of a mutual investment from both parts: by clients stepping over thresholds and daring to repossess their life through engagement and by therapists trying to 'step back' and allow clients to find their own pace. The process of engagement in activity was, therefore, identified as a spur to the participants in taking risks and committing themselves to the life they had through activity. Moreover, the actual making of creations unfolded in an evolving process, stimulated by an ongoing social exchange between clients and therapist, a process in which ideas were given shape in their material realisation. A salient, social component was identified, since creative activities formed a natural meeting-place for participants, stimulating social relations that were facilitated through processes of engagement and actual doing. Furthermore, creative activity was found to have the potential to reach alternative horizons of meaning, perceived as meanings that lay beyond the tangible creative activities. This was seen on an immediate level, since creative activity involved planning – deciding, for example, for whom a creation was being made – which, in turn, implied reaching towards a possible future. Being created for family and friends, creations were endowed with symbolic meaning as a form of reminiscence and allowed to communicate issues around death and possible new beginnings.

In conclusion, Study I identified components of the individual investment made by clients and therapist, as well as their joint engagement in creative activities that can facilitate the client's experiences of self as an active person, in connecting and re-arranging connections with life in the face of life-threatening illness. This study raised further questions as to the personal experiences of the client's engagement in creative activities during palliative OT which was the focus in Study II.

In **Study II**, the aim was to investigate the meanings that people with advanced cancer ascribe to engaging in creative activity in palliative occupational therapy.

The participants' subjective experiences of engagement in creative activities were identified as easing life in proximity to death and providing opportunities for creating new ways of living. Participants' engagement in creative activities entailed ongoing processes that involved confronting some of the consequences of advanced cancer, experimenting with new possibilities and acknowledging personal capacities and potentials. As part of this process, confrontations with central issues appeared to take place through engagement in creative activities, in that clients encountered losses and limitations, which in turn stimulated them to move on. A social dimension was strengthened through an increased sense of belonging and of mutual understanding among the patients. Creative activities were further identified as a means to enable the co-existence of experiences that participants identified as contradictory and difficult to unify, such as one moment enjoying life and the next moment being acutely aware of the uncertainties of impending death.

In summary, the findings of Study II revealed creative activities to be a lived process of developing ways for the participants to handle current challenges and situations, involving existential concerns and declining physical abilities, by engagement and the use of their body in creative work. In addition, the findings extended to Study I by

providing insight into the ways in which processes of engagement in creative activities were experienced by the individual. The results of this study indicated that engagement in creative activities in palliative OT could be a means for the participants to address issues pertaining to situations, not only in therapeutic settings, but also in everyday life outside the therapeutic setting. New questions were raised concerning activities in the everyday life of people with advanced cancer. Therefore the focus in Study III and IV was directed at exploring activities of everyday life at home for people with advanced cancer.

Study III aimed to describe and explore the everyday activities of people with advanced cancer in relation to time, location, social engagement and experience. The results showed that the participants spent most of their time at home. The participants' daily activities were dominated by self-care and leisure and social engagement was limited to their immediate family and close friends. The symptoms of cancer influenced the participants' occupational patterns with respect to night and day to an extent that also affected their activity in time, location and social context.

Common needs among the participants were identified in several contexts. In the activity context, there was a need to have something to be engaged in on a daily basis. In the geographical context, a need was expressed to get away from home. In the social context, there was a desire to increase time with family and be with other people who had similar cancer conditions. Further, in regard to being with other people with advanced cancer, apprehension was identified in some participants who were concerned with excessive focus on illness.

Rhythm in daily activities was identified as combinations of activities of routine and of activities of change conducted in individual compositions. Activities both of routine and of change had their own distinct value. Routines supported ordinary days providing

a sense of familiarity associated with continuation and structure. Change was valued for stimulating different ways of thinking and by including qualities of challenge, unpredictability and development. Moreover, the results showed that the participants were striving to establish and maintain rhythms in order to achieve a sense of satisfaction. Taken together, the results of Study III highlight that participants with advanced cancer strive to create an ordinary day with individual rhythms and show how that can be established by means of engaging in activities of everyday life. The results from this study led to a quest for deeper insights into ways in which people with advanced cancer create meaning through activities in everyday life which motivated Study IV.

In **Study IV** the aim was to explore and understand how people with advanced cancer create meaning and handle everyday life through activity. The results demonstrated how participants fashioned stories that were useful to them in living their everyday life with advanced cancer, by talking about and enacting daily activities. A meta-narrative of ‘saying goodbye in a good way’ illustrated how the participants’ everyday lives were directed towards the future, which meant that the end of life lay ahead as they strove to conduct the remainder of their lives as a farewell in what to the participants was a good way. Another narrative was identified as ‘I am healthy although I am sick’, which allowed participants to explore the contrast between feeling healthy and being severely ill, while emphasizing that they were healthy despite severe illness. The identified narratives illustrated the challenges the participants experienced in creating desired stories in negotiation with their socio-cultural context. For example in trying to make the best of the time left to them and their families and friends. Furthermore, daily activities were identified as providing a familiar framework that could stimulate agency and render enriching and life-confirming experiences. Activities associated with

enriching and life-confirming experiences were emplotted as stories named 'My little Mecca', in which participants found respite and a sense of consolation. These different narratives seemed to provide a freedom in creating alternative meanings and interpretations of daily life as a counterweight to the reality of the disease, but also as strategies for handling the consequences of the illness.

Taken together, the results indicated that the participants mobilized activities and strove to convey stories of favourable impressions as a means of handling the challenges they were facing. The creation of meaning, in what remained of life in the face of death, was not only guided by a personal quest to be healthy, by a striving to maintain routines or by the creation of spaces for completion, but it was also influenced by the given socio-cultural environment.

GENERAL DISCUSSION

MAIN FINDINGS

The overall aim of this thesis was to enhance knowledge about how people with advanced cancer experience their engagement in activities, and how such activities may be useful when living with life-threatening illness.

Each of the four studies comprising this thesis focuses on different aspects of engagement in activities. Together, all the findings showed that engagement in activity offered broader opportunities for working with and processing issues brought on by living with advanced cancer, whether in the context of palliative OT or from the context of home. More specifically, the results identified ways in which engagement in activity could serve as a vehicle for experiences of healthiness, connectedness and sociality, and as a refuge where the participants could refuel, take time-out and rid themselves of frustrations in the midst of life-threatening illness. Simultaneously the results indicated that engagement in activity could serve transformative processes involving confrontations, risk-taking and courage. Furthermore, the findings shed light on aspects of meaning and meaning-making processes promoted through engagement in activities. These main findings from all four studies will be discussed in the following sections.

EXPERIENCES OF HEALTHINESS IN THE MIDST OF INCURABLE CANCER

A key finding applicable to all four studies was that engagement in activity was identified by the participants as enabling experiences of healthiness and associated competence in the actual proves of doing. This finding needs to be understood in the light of the participants' condition, all being seriously ill and at times experiencing ongoing decline.

First of all, findings from the studies (Study I & III) showed that the actual conduct of activities was experienced to reassure the participants in their perception of being healthy, as they had been prior to becoming ill. This might be understood in the light of basic assumptions in occupational science, that everyday life capacities and health can be achieved and maintained through the individual's engagement in simple activities (Bateson, 1996; Molineux & Whitford, 2005; Wilcock, 2006). Consequently, the studies provide empirical support for understanding how experiences of health and engagement in activity may be related.

The identification of links between engagement in activities and experiences of healthiness relates to discussions concerning (the notion of) health, and what health may actually involve for people who are dealing with advanced cancer (Jacobsen, 2007; Kagawa-Singer, 1993). In regard to such discussions, Kagawa-Singer (1993) proposes redefinitions of health for people with cancer and suggests that the ability to maintain a sense of integrity and productivity is central. Indeed it is important to reconsider current understanding of health and illness as a whole, but for the people with advanced cancer it may be even more important to investigate ways in which experiences of being healthy come about. In other words, existing research addresses the understanding of health and illness of people with cancer, but to a lesser extent addresses how these people come to experience health when severely ill. It can be argued, that the findings of Study I, II and IV complement knowledge relevant to understanding how experiences of health may be achieved in the face of dying.

Notably, the participants seemed to be aware of their need to be healthy both in their way of thinking about their circumstances as well as in their conduct of daily life. The findings suggested that engagement in activities, such as working in the garden, was experienced by participants as a confirmation of healthiness, since it showed that they were able to undertake practical chores, despite pain, fatigue or other disturbing

symptoms. Thus, it could be proposed that by performing activities the person with advanced cancer could take agency and literally demonstrate competence in bodily action. Such performance of activities could also be seen and acknowledged by others, which in turn implied social reassurance. In a similar vein, findings from a study by Lindquist, Widmark & Rasmussen (2006) suggest that feeling healthy is closely related to the ability to perform activities in everyday life. The relationship between the conduct of activity and experiences of health is also described in the literature (Wilcock, 2006; Pörn, 1993) but scarcely addressed in empirical research. Furthermore, existing research (Ville & Khlal, 2007; Kagawa-Singer, 1993) and the results from the studies in this thesis (I, II & IV) suggest that living with advanced cancer involves experiences of both 'life as usual' (healthy) as well as 'life as ill'. Such dichotomies are reflected in the work of Salander, Bergenheim & Henriksson (2000), who has proposed that for people living with advanced cancer, time can be thought of as 'time of disease', when the individual's time is dominated by illness, and 'time of everyday life', in which life continues as usual. However, in contrast to the distinction proposed by Salander, Bergenheim and Henriksson (2000), the results in study II and IV identified, that the experiences of being healthy and severely ill were experienced to be co-existing when participants were engaged in activity. Engagement in activities was identified as supporting participants in living simultaneously with both the detrimental aspects of life with cancer and the enriching and generative experiences that were also part of life. Thereby activity not only offered a way to experience healthiness, but also provided a means to express multifaceted ways to live life. These findings relate to discussions on the understanding of health as brought forward by Kagawa-Singer (1993) and Salander, Bergenheim and Henriksson (2000) who argue that defining health and illness as opposites on a continuum may be too narrow for those living with cancer. The findings from the studies in this thesis complement such propositions by

identifying oppositions, such as health and illness, as being perceived as co-existing by people with advanced cancer. These findings accentuate a need not to limit people with advanced cancer to restricted perceptions of health and illness, but rather to reassure them that there are opportunities for conducting life in rich and nuanced ways. Still, it should be noted that experiences of being healthy are not tied only to the ability to engage in activity, and that other ways of experiencing healthiness should be taken into account. For example, Antonovsky (1987) has proposed that ‘sense of coherence’ (SOC) is closely related to health, and this may also be a key consideration when people are striving for health in the midst of severe illness.

Taken together, the findings of this thesis contribute to the field of research on engagement in activity as being an important source for achieving experiences of healthiness and enabling the co-existence of different and complex aspects of life.

CREATING CONNECTIONS INVOLVES CONTINUITY AND DISCONTINUITY

From the findings, the ongoing creation of connections and disconnections was identified (Study I) as a potential of engagement in creative activities, when living with advanced cancer. In a parallel vein, several researchers (Charmaz, 1999; Svidén, Tham & Borell, in press; Ville & Khlát, 2007) identify how in times of disruption, people with severe illness seek to create a sense of continuity. Findings from Study I and III extend such knowledge by identifying how the actual doing of activities provided ways to create connections as a form of continuity in the participants’ everyday life and highlight the significance these connections had for the participants. For example, creative activities were used by participants to create connections by integrating experiences from their past into current productions, using colours, for example, associated with travels to other countries (Study I) or aspiring towards familiar routines

by composing rhythms of daily life, close to the rhythm they had before illness (Study III). However, in most other studies on the creation of continuity the connections being made are primarily with reference to the past, trying to re-establish or continue previously known ways of doing (Raunkiær 2007; Svidén, Tham & Borell, in press). The findings from the studies in this thesis extend such knowledge by showing that connections not only concern bringing the past into the present, but also link the various environments in which the person is engaged, such as the therapeutic setting and life at home. Furthermore, activities were used as a way to communicate and reach into an uncertain future by creating things that, for example, participants wanted to give to others (Study I, & II) or by fashioning stories that supported establishing mutual positive experiences and memories for family and friends (Study IV).

Another aspect of connections, identified in the current studies, reflected ways of *disconnecting* as participants confronted consequences of their illness. Such disconnections became visible as participants were forced to give up activity they could no longer undertake (Study I, II, III & IV) and took on the challenge of experimenting with new approaches, letting go of previous patterns of involvement in activities, roles, etc. Disconnections were, therefore, identified as being closely related to connections. Together, the findings on connections relate to discussions on continuity theory (Mishler, 1999). One position taken in such discussions is proposed by Atchley (1999), who argue that people strive to continue their previous lifestyle and so try to create a sense of continuity, between past and present events. In opposition Kotre (1984) and Bateson (1989) argue, that the lives of people they have studied are composed and improvised over events marked by interruption and conflict. The findings in this thesis (Study I & III) suggest that people with advanced cancer create continuations as well as discontinuations and that these peoples lives are, therefore, not built simply on one of these dimensions but on an interplay between both. Furthermore, it might be argued

that the dynamic interplay between both dimensions facilitates change and transformation, in that connections representing continuity and familiarity (Study III & IV) can be seen to provide a safe base from which to disconnect and create new and alternative ways to conduct daily life.

There is no doubt, that the findings of this thesis seem to be in accordance with some of the existing theoretical and empirically based propositions (Atchley, 1999; Bateson, 1989; Mishler, 1999) about continuity and discontinuity, and that they complement such existing knowledge by showing more specifically how creations of connections and disconnections may take place through work with literal activities and materials. In addition, the participants' rearranging of connections and disconnections might be viewed as a means of creating meaning through links made between significant experiences throughout the individuals' life trajectory.

REFUGE IN ACTIVITIES

The findings in all four studies (I –IV) indicated that the participants' engagement in activities provided them with a refuge and a sense of respite from their concerns about their illness, their families, dying, pain and suffering. This finding is in line with other studies that have shown, for example, that day-care as a parallel to palliative OT can be experienced as a safe retreat (Lawton, 2000) or palliative care can be experienced as a lived retreat (Öhlen, 2000) in which alleviation of distress is made possible.

Interestingly, beyond palliative care being a place for refuge, all four studies in this thesis showed, that engagement in activities were also experienced as a refuge. For example, the findings from Study I and IV identified that engagement in activity could facilitate experiences of peace and enrichment. Similar findings have been identified by Nygård and Borell (1998), who brought forward, the finding of 'resting in activity', based on a study of everyday life of two women with dementia.

A noteworthy finding in Study II was, that activities ascribed to be enriching simultaneously provided the opportunity for participants to rid themselves of frustration and sorrow. This suggests that respite in activity is not merely about taking time out or doing things that are experienced as consoling and pleasurable, but also about having an arena in which people with advanced cancer can express the negative and debilitating sides of their current situation (Study IV). These findings deviate from those of Lawton's (2000), who in her studies identified day-care as an 'alternative' reality associated with escape rather than also providing an opportunity for dealing with negative and detrimental aspects of facing life-limiting illness. Furthermore, seeing that the findings from Study II and IV showed that participants experienced respite and refuge in activities (Study II, and IV) in palliative OT as well as in other contexts of everyday life, it could be argued that the experience of refuge through activities might be independent of context.

As a whole, the suggestion of these findings, that activities afford a refuge for these participants, has parallels in the findings of other studies in which people with severe illness find opportunities for rest and alleviation. In addition, the findings from this thesis indicate that refuge may also involve the expression of pain and suffering. In other words, ways to experience a sense of refuge and freedom may be achieved through the challenges inherent in activities.

ACTIVITIES AS A MEANS TO ACHIEVE CHANGE

Across all the four studies, activities that carried certain qualities were identified as being closely related to salient changes, that the participants highlighted as keys in their endeavour to make the best of the life remaining to them. These qualities included, for example, ideation, suspense/unpredictability, investment, challenge, construction and enjoyment (Study I – IV), all of which are closely related to qualities associated with

play and creativity (Csikszentmihalyi, 1997; May, 1984; Winnicott, 1971). These qualities were identified in a variety of activities and, judging from the findings in this thesis (Study I-IV), did not seem to belong to a certain group of occupations, but were rather associated with the transformative processes of experiment, change and development that the participants emphasised. Not surprisingly, the findings of the current studies identified the fact that engagement in activity enabled the participants to generate creativity for dealing with their everyday life situation. These findings are shared by a number of studies showing that people with severe illness work with their situation in innovative ways and adopt new value and meaning through various kinds of activities, ranging from material arts & crafts (Heywood, 2003; Kennett, 2000; Luzzatto, 2003) to the telling of narratives (Bury, 1982; Crossley, 2003; Hydén, 1997; Mattingly, 1998). As an extension to such knowledge, the findings from the studies in this thesis pinpointed some of the conditions and qualities adhering to activities that were significant to creativity. Firstly, the findings showed that conditions relating to familiarity (Study III) and to a known and safe base (Study IV) functioned as a platform that in turn gave rise to the exploration of new activities and innovative ways of approaching life. Meanwhile in Study I, the creation of connections to previously accustomed lifestyles might be viewed as providing a base from which the participants could then disconnect from activity that did no longer ‘work’ because of the illness and proceed to try out new approaches. Similarly, in Study III the findings showed that participants created rhythms of routine activities – which, like connections, can be seen as representing the familiar and known – in conjunction with activities that differed from their routine by involving innovation and challenge. These findings appear related to the ‘potential space’ proposed by Winnicott (1971/1995), who from a psychological perspective suggests that play and creativity occur in the potential space. According to Winnicott, this potential space is a theoretically identified construct, in which the

individual can experience a safe base supportive of play and creativity (1971/1995).

With Winnicott's proposition in mind, the findings from Study I, III and IV on the creation of a safe platform can be seen as analogues of the potential space stimulating or allowing the creativity of the adult participants with advanced cancer. In relation to Winnicott's ideas, the results of these studies shed light on how it is possible to establish platforms of security from which people with advanced cancer may begin an exploration of new and alternative formulations of their situation. Examples might be the generous environment that was identified (Study I) or the routines that provided a sense of familiarity (Study III and IV).

The findings from Study II in particular identified that engagement in activities could involve processes of going through confrontation, experimentation and coming to an acknowledgement of one's condition and one's individual resources (Study II). If the processes identified are seen in relation to stages like those described by Kübler-Ross (1969/1995) or to the typology of lived suffering as described by S.R. Hansen (2003), engagement in activities may present possible ways to address aspects of dying and suffering. The processes identified can also be associated with those creative aspects of play that are a way for children and adults alike to explore, adapt and give meaning to their worlds (Bundy, 1991). Thus the processes identified (Study II) of confronting, experimenting and coming to an acknowledgement that are enabled by engagement in activities do not in general terms represent new knowledge, but have specific application to ways participants with advanced cancer may try out, recast, discard and invent new approaches to their current life through the activities they engage in. Thereby these processes may be viewed as examples of first steps in developing knowledge about the possible stages that people encounter through engagement in activity useful to 'handle' current situations, when living with advanced cancer.

The identification of confrontations as a central aspect of engagement in activities (Study II) showed, that engagement in activity can involve obstacles and trouble as well as enjoyment. Interestingly enough, the finding of confrontations through working with materials draws attention to the complexity of engagement in activity as a resource and to the fact that a one-sided view of activity can be problematic, since it may fail to recognize the risks as well as the potential advantages embedded in the challenges that people can encounter when engaging in activity.

Such aspects of activities as ‘confronters’ may be useful to further ways in which to utilize activities as therapeutic means in stimulating change and development.

The use of materials for emotional processing has a long tradition in psychodynamic inspired therapies such as art therapy (Pratt and Wood, 1998). Working with processes concerning end of life issues using such materials is not new by itself, but the findings from this thesis provide suggestions on how such processes may be facilitated by confrontations inherent in engagement in activities. In addition, the findings suggest that, through the processes facilitated by engagement in activity, the participants do not only work with emotional issues. Rather the process of confrontation, experimentation and coming to acknowledgement involves the ‘whole person’, in other words involves bodily, emotional, social as well as existential issues. Consequently, as a means to address some of the multiple consequences of advanced cancer, it might be of value that people in such circumstances are supported and given opportunity to engage in activity in palliative care interventions as well as in other contexts of everyday life such as at home.

Confrontations were encountered in specific activities that participants engaged in, as well as in the composition of everyday living. This was seen in Study III, when consequences of illness interfered with the activity rhythms of daily life and in Study IV, when they influenced the participants’ employment and storying of their current

situation in the given socio-cultural context. A key in these findings was that the creation of rhythms (Study III) and stories (Study IV) created through engagement in activities contributed to the participants' sense of satisfaction. Together, these findings suggests that engagement in activities is not only useful in working with aspects of life-limiting illness on an individual level but also as a means for establishing and recreating structures of temporality and narrative configurations that counteract the imbalance of illness and support aspects of meaning in daily life. These findings are in line with other studies (Raunkiær, 2007; Svidén, Tham & Borell, in press) showing that in the face of severe illness people strive to maintain and re-establish daily life activities, as well as constantly revising stories as an active mediation of life events (Crossley, 2003; Hyden, 1997; Polkinghorne, 1996; Ville & Khlát, 2007). In that regard it could be argued, that the construction and reconstruction of rhythms and stories (Study III & IV), created through engagement in activities, contribute specific knowledge about ways in which activity may be used in composing and recomposing daily life as possible strategies to negotiate the consequences of severe illness.

SOCIALITY IN THE FACE OF IMMINENT DEATH

Not unexpectedly, the findings from all four studies identified that the participants with advanced cancer experienced social losses and dilemmas in a number of ways. For example, participants across all studies brought up experiences of being stigmatised. The findings showed that the participants experienced themselves as alienated, intimidating and deviating, particularly in relation to social contexts in which people were not ill. Goffman (1963) have drawn attention to the stigma attaching to people who possess attributes that make them different from others and who feel reduced from a normal person to a discounted one. Studies on cancer and stigma confirm that people with cancer are prone to experience stigma, often due to changes in appearance caused

by cancer (Sonntag, 1991; Wilson & Luker, 2006; Ziebland & McPherson, 2004). The findings in this thesis support existing knowledge on stigmatization of people with cancer and draw attention to ways in which stigma may be negotiated. In that regard, H. P. Hansen's (2007) study on women's experiences of hair loss induced by chemotherapy identified how these women use practical aids, or what she calls 'body adornment', such as wigs and make up, to regulate the body as a way to minimize stigmatization. As an extension to such strategies, the findings of Study I, II and IV showed that participants used different strategies to negotiate idiosyncrasy by reframing stories and enacting activities. For example, the participants deliberately chose to carry out activities, such as decorating their home environment, which, although strenuous, they associated with 'normality' and so as ways of mediating and demonstrating to themselves and others that they were not all that different despite advanced cancer. Goffman (1971) suggests that people's ways of presenting themselves guide impressions in order to sustain and possibly understand reality and self. The findings of this thesis provide empirical support to Goffman's ideas by showing ways in which activities may present tools for 'presentations of a self' that is not confined to being a cancer patient, but also to being a 'healthy' person living a 'normal' life, whatever that means under the circumstances.

Another aspect of sociality, identified in the findings (Study I, II & IV), was that participants experienced coming together with others in similar conditions as themselves as confronting. At the same time, the findings of Study I and II suggested that engagement in activity enacted and pursued alongside others formed the grounds for companionship over time through processes of actual doing. The activities that participants engaged in became occasions for sharing that were often actualized through exchange of ideas and choice of materials, colours and shapes. Related findings, that activity can be viewed as meeting places and social fellowship, have been

identified in studies of people with dementia (Josephsson, 1994; Josephsson, Bäckman, Nygård & Borell, 2000; Öhman, 2007). In addition, the studies in this thesis also showed that as much as participants expressed the desire to be with people who were in similar circumstances, they also found it problematic, since at times those social events functioned as reminders of their own mortality and illness. Literature (Zachariae, 2004; Jacobsen, Jørgensen & Jørgensen, 1998) and research (Grønvold et al., 2006; Söderbäck et al., 2000; Taylor & Currow, 2003) on the needs of people with cancer often highlight the need for social exchange among people with cancer. However, the social needs of people with advanced cancer, as identified from the studies in this thesis, are more nuanced; as the results showed that it was not only desirable to be with people in similar conditions. Rather the findings indicate that sharing mundane activities and topics other than disease are, at times, preferred grounds for social interaction (Study I, II & III).

Furthermore, the findings from the studies demonstrated different forms of sociality experienced through activity related to levels of engagement. Participants, for example, often engaged in doing each of their own activity as a level of parallel engagement (Study I & II). During activity, participants exchanged ideas and experiences through conversation or were simply present alongside one another and thereby ‘witnessed’ each other’s work. Another level of engagement was seen, when participants actively followed the activities of others without carrying out any activity themselves.

Similar findings came to the fore in Study III and IV, where participants also highlighted following and taking active part in what was going on around them in various settings, without necessarily any actual doing but rather an engagement characterized by a sense of active involvement. Different levels of engagement, or participation in activities, have been identified by other researchers on occupation (Haley & McKay, 2004) but not in regard to people with advanced cancer. Central to

the findings is the fact that people with advanced cancer strive to be engaged and preferably in social circles. Therefore it might be to their advantage, if palliative support is developed to assure opportunities for engagement on various levels in parallel activity, as well as for following each other without necessarily having to perform.

Although it is well recognized that people with cancer are prone to social loss accompanied by distressing loneliness (Kissane et al., 2004; Rokach et al., 2007), the amount of time, identified in Study III, that the participants spend in solitude, and their experiences of being alone, was remarkable and raises questions as to how experiences of loneliness can be alleviated. In that regard, the use of internet was identified as one alternative form of sociality that several participants benefited from. Since the social potential of the internet, for people with cancer, is rarely addressed in research, this seems a relevant area to pursue in future research.

One aspect of sociality, that has particular relevance for interventions, was the finding in Study I that a generous receptive environment was crucial for engagement and that it was co-constructed by clients and therapists. There is limited research on how to create environments that facilitate activity in therapeutic settings (Guidetti, 2008; Haley & McKay, 2004), and Study I contributes to such knowledge in showing how, by mutual investment and by daring to expose personal vulnerability, clients and therapists contributed to a generous environment, which in turn fostered the clients engagement. These findings can have implications for practice and for the therapist by drawing attention to how stimulating environments are created in an interaction between therapists and clients/patients. In addition, these findings complement the focus on client-centred approach emphasized in contemporary health care services (Cooper, 2007; Sundhedsstyrelsen, 2007) by suggesting that intervention is dependent on the

ongoing transactions between the client/patient and the therapist/ health care professionals.

A final feature, related to sociality enabled through engagement in activity, is the findings related to social exchange and reciprocity identified in Study I, II and IV. The creation of material objects (Study I & II), that were given to others, mediated possibilities for participants to leave something that could ‘live on’ and also enabled them to give something back to those family and friends who cared for and looked after them. The creation of their artefacts (Study I & II) became ways for participants to engage in social exchange of give-and-take, enabling continued relationships of reciprocity (Pels, Hetherington & Vandenberghe, 2002; Mauss, 1950/2002). Another finding demonstrating how social reciprocity, giving something back, can be performed through the activities of everyday living was identified in the participants’ way of emplotting the story of ‘saying goodbye in a good way’ as illustrated in the results of Study IV. To sum up, these findings (Study I, II & IV) amplify the roles that activity and the product of activities (such as artefacts or emplotted stories) may play in establishing and maintaining social relationships. Nevertheless, to further understand how activities may be utilized as strategies in dealing with socially detrimental aspects of living with advanced cancer, additional studies in this area are needed.

REFLECTIONS ON MEANING AND ENGAGEMENT IN ACTIVITY

Meaning and meaning-making in everyday life take on profound importance for people living with advanced cancer in the sense that their lives have been radically thrown off course, leaving them in a situation where the meaning of everyday life and the meaning of what they are doing and can do require reappraisal. Therefore there is a need for creating new or alternative meanings in the life remaining to them. In that regard, the

findings from the studies in this thesis can be said to illustrate aspects of meaning through engagement in activity in different forms: as connections (Study I), as lived processes of confronting, experimenting and coming to acknowledgement (Study II), as rhythms of activity (Study III), and as ways of narrative employment enacted as well as told. The findings thereby provide empirical illustrations related to experiences of meaning and how meaning may be created in various forms through activity when living with advanced cancer. In the literature on occupation, the notions of meaning and meaningful activity are presented as central in relation to engagement in activity (Jonsson and Josephsson, 2005; Persson, et al., 2001; Reilly, 1974; Zemke, 2004). Yet what meaning is, and how it is created, and how to distinguish meaning from meaningful activity, are complex questions that still remain to be addressed. One theoretical resource that can be used to understand if and how activity is meaningful is activity theory (Leontjev, 1973). According to Leontjev (1973) meaningful activity is experienced when there is a correspondence between the external goal of a given activity and the person's motive for the activity. However, the findings in this thesis (Study IV) might suggest that meaningful activity comes about not only in a correspondence between goals and motives, but also in a highly dynamic process of discovery generated by the individual's engagement. In other words, the findings suggest that, when engaging in activities, the participants for example experienced the suspense of not knowing where the activity would lead (Study I), which implies that goals and motives are not stable entities but rather in constant development. The findings from all four studies showed that engagement in activity that was perceived as creative could involve experiences of forgetting time and being fully absorbed. These findings relate to the notion of flow, characterized by similar experiences (Csikszentmihalyi, 1996). As an extension to flow theory, Persson (2001) has used an occupational perspective to show that meaning is closely related to

creativity and flow. However, in flow theory (Csikszentmihalyi, 1996) the experience of flow is said to occur when there is a correspondence between the challenges that the activities present and the skills of the individual. In Study II, the lived meaning was identified as a process involving confrontations and risk-taking among its central features. Therefore, although experience of flow and experience of meaning are not the same, the findings of Study II could lead to speculations that experiences of flow and of meaning can also be achieved when there is discrepancy between an individual's capacities and the challenges they are facing, and that other denominators than 'just the right challenge' are at play.

The results of Study III could tentatively be related to aspects of meaning. This study (III) identified that through engagement in activity, people create rhythms in their daily life composed by activities of routine and change, which are ascribed different kinds of value. For example, routine activities were often valued for providing some sense of 'ordinariness', whereas activities of change stood out from routines and often carried significant values, associated with enrichment and experiences that assisted participants in transformative processes such as development and learning. As a whole, rhythm might be seen as a form of composing meaning in the individual's daily life that is shaped in accordance with their social climate and the context of time and location. This relates to Holzkamp (1995), who proposes that people live life in dynamic relations between what he refers to as the 'cyclic conduct of life' and the 'actual life'. He defines the 'cyclic conduct of life' in line with routine activity, which is described as reproducing and organizing activities that help to maintain everyday life in familiar ways. Holzkamp (1995) further suggests that the 'cyclic conduct of life' support the individual by providing relief from constant awareness of how to approach everyday life. This corresponds to the values of familiarity and ordinariness that participants in Study III ascribed to routine activities. The other dimension that Holzkamp (1995)

describes as the 'actual life' is associated with experiences of happiness, flow and meaning. This relates to the dimension of change, identified as an aspect of rhythm (Study III), which was associated with variation from the routines and with experiences of particular value. Reflecting the ideas of Holzkamp (1995), the notion of rhythm can be understood as a process under constant construction, engaged in by the individual as a way of creating a meaningful whole in everyday life. However, whereas Holzkamp (1995) seems to suggest that meaning in particular is experienced in activities defined as the 'actual life' (parallel to activities of change), the results of Study III suggest that meaning is experienced in the combination of activities of routine with activities of change.

By approaching experiences of activity from a narrative perspective, Study IV identified how activities provided the participants with arenas for creating alternative meanings and strategies useful in handling everyday life with severe illness. According to Bruner (1990, p xiii), understanding aspects of meaning is about trying 'to understand how human beings interpret their worlds and how *we* interpret *their* acts of interpretation'. He emphasizes, that people in interaction with one another form a backdrop against which to create meaning as to breaches in and deviations from normal states of human conditions. Bruner thereby proposes to understand meaning as a process of meaning-making shaped in socio-cultural contexts especially stimulated in times of deviation and in situations in which people experience disruption, such as an advanced cancer. The findings of Study IV are in line with Bruner's proposal and confirm to his ideas empirically as the participants' fashioning of stories can be viewed as processes of meaning-making that were facilitated by the critical circumstances of life-limiting illness. By extension and based on the findings from the studies in this thesis, it could be argued that engagement in activity, such as the making of material creations in crafts (Study I & II), can be seen as a non-verbal idiom of narrative

emplotment that allows the embedding of numerous stories. This relates to features of narrative meaning-making involving what Bruner (1990) identified as establishing subjunctivizing realities as arenas in which alternative and different interpretations of life can co-exist. For people living with advanced cancer, this means that the realities of living can be emplotted in ways that allow for complexities such as the co-existence of being healthy and being severely ill. Engagement in activities may, therefore, serve as such arenas for the participants with advanced cancer to create and experiment with possible meanings.

To further reflect on the creation of meaning in relation to engagement in activities, Ricoeur (1984) suggests a link between enactment of activity and meaning-making that can be created through expression, communication and potential interpretation embedded in the performance of activity (Uggla, 1994). In relation to the results of the studies in this thesis, Ricoeur's proposal can be understood in the sense that activity can potentially nourish the creation of new alternative meanings. In other words, when participants engage in activity and shape different stories, as, for example, in Study IV, they express and communicate aspects of their situation, which in turn is a way for them to create new and alternative meaning in their ongoing life. The findings provide, then, empirical support for engagement in activities as possible means to enable the processes of meaning-making. Furthermore, Ricoeur's reasoning rejects emplotment of materials such as facts, conditions, events and wishes as an exact mirror of reality (Josephsson et al. 2006). The findings from this thesis, with the creation of connections and disconnections (Study I) and participants' emplotment of 'Mecca' as an arena for respite and enrichment (Study IV) need not precisely mirror a reality. Rather these findings complement knowledge on how engagement in activities may be useful for the individual in establishing a multiplicity in the understanding of their circumstances, beyond their being defined by advanced cancer.

In summary, most of the existing research (Hutchings, 2007) concerning people in advanced stages of cancer emerges from the prevailing paradigm of biomedical sciences, and results from studies of such perspectives often show that activity is useful in having certain effects, such as providing relief from pain or experiences of competence. However, these studies address to lesser extent how such effects come about and how people can use engagement in activity to find ways to tap into their own particular resources to handle their current situation.

The findings of the studies in this thesis supplement existing research by showing how engagement in activity can potentially function as a resource for people with advanced cancer to confront and work-through some of the consequences of incurable illness.

Through engagement, activity challenges the individual and stimulates the discovery of personal and socio-cultural resources that the person may draw upon to handle everyday life through taking agency, transcending grief and experiencing enrichment and completion in the face of impending death.

The findings, however, do not present conclusive answers but rather offer an initial widening of focus to include the potential inherent in activity. Certainly the destructive aspects of advanced cancer with bodily decline, suffering and continuing losses should not be underestimated. On the other hand, as illness trajectories of cancer are steadily changing as periods of living continue to be prolonged, due to improved treatments, it is crucial to embrace and enable the immense resources that people seem to possess, even in the face of impending death.

METHODOLOGICAL CONSIDERATION

Doing research about the activities of people with advanced cancer presents a constant challenge throughout the research process, as it involves people who are prone to be particularly emotionally fragile. This entails ethical considerations and the need for respect and gentleness towards the people involved (Hansen, S.R., 2003; Raunkiær, 2007). Choosing the methods for the research studies in this thesis demanded considerations about the ramifications of these choices in the quest to gain insight into experiences of participants who were living the last period of their lives while simultaneously treating these people respectfully. Furthermore the validity of studies included needs to be discussed. Validity is concerned with the credibility of the studies (Maxwell, 1996) and in that regard some questions should be asked. For example, were the sampling procedures and methods for data collection, using interviews, TGM diaries and participant observation, appropriate for answering the questions raised? And to what extent can the findings be trusted to illuminate engagement in activities of people with advanced cancer?

The following section is a general discussion of some of the methodological choices, and the possible implications these choices may have had for the validity of the studies, that form the basis for this doctoral thesis.

Sampling

Purposive sampling was used for recruiting participants to the studies in this thesis. According to Luborsky & Rubinstein (1995), purposive sampling is a practice in which participants are deliberately selected to represent explicit predefined traits or conditions. Deciding on what these predefined traits should be, as criteria for sampling, raised a number of considerations. In this thesis the sampling criteria became increasingly more specific from Study I – IV. For example, in Study I a central

inclusion criterion for eligible participants was that they were attending the creative activities in palliative OT. This criterion meant that participants in the study had life-threatening illness as their common denominator without further specificity of diagnosis. This led to the inclusion of a client who was a stroke survivor, whereas the other clients all had advanced cancer. Although this might not have influenced the results in regard to the aim of the study, it should be taken into account that being a stroke survivor presents different conditions from those of people with advanced cancer. In both Study I and II the sampling criteria did not specify that the participants had to be in specific palliative stages, and the clients/patients who participated in the studies all turned out to be people who had a long palliative phase with more than an estimated two months of life remaining. This was especially the case in Study II with most of the participants being women with breast cancer, who commonly have a long disease trajectory. Factors like length of disease trajectory may affect the results of a study (Luborsky & Rubinstein, 1998; Sandelowsky, 1993). More specific to these studies, being in the long palliative phase might have carried the implication that participants were more actively engaged in creative activities than if they had been in later stages of illness with a short palliative phase. Therefore the fact that participants were in early stages of prolonged palliative care should be taken into account in understanding the findings of these studies. This experience from Study I and II led to a more careful formulation of inclusion criteria as regards to participants' disease trajectory in subsequent Studies III and IV.

One concern that might be highlighted about the sample of participants in Study II was that four of the participants from Study I continued as participants in Study II with another research question. This matter could give rise to pre-understandings, on the part of the researcher, and lead to difficulties in bracketing, which is an important part of phenomenological analysis (Karlsson, 1995). In response to such concern, a diary of

impressions and thoughts was kept during the research process to assist continuous critical reflection on how both the researcher and previous findings in Study I might influence the data and analysis.

Seven participants were sampled as a sub-group for interviews in Study III, and the same seven participants also participated in Study IV. This sub-group was recruited during the first year of data collection for Studies III and IV and thus was only sampled from the participants, who had joined the project during that initial period. The sub-group was, therefore, not representative of the entire group of participants. However, as it was an exploratory study, the sampling was not aimed to be representative for the entire group but rather to gain in-depth insight to experiences of the participants.

Reflections on generation of data

Qualitative interviews were used as a method for the generation of data in all four studies.

A concern that might be raised about Study I was that the participants were subject to only one interview, and it could be argued that a single interview of each participant is insufficient to unfold individual's experiences (Reissman, 1993). A consequence of single interviews was that questions that arose from initial analysis of the data could not be taken back to the participants for further elaboration (Coffey & Atkinson, 1996).

The content of the identified categories could possibly have become more substantial, and relationships among the categories could have been further developed, if several interviews had been carried out. On the other hand, Holstein and Gubrium (1995) argue that, 'one cannot expect answers on one occasion to replicate those on another because they emerge from different circumstances of production'. Their line of reasoning implies that each interview should be viewed as an entity by itself and so the findings

of Study I can be seen as pertaining to the particular occasions on which they take place.

Although the results of Study I were based on interviews, both of clients and therapists, the results reflect a preponderant focus on the clients. The perspective of clients, as well as of therapist, could possibly have been weighted more evenly in the analysis. This might have influenced the findings further by showing up aspects of the social processes taking place during creative activities.

Based on the experiences from Study I, in which participants were only interviewed once, Study II was designed with several interviews of each participant. This choice was made to achieve depth in the interviews, in order to explore the meanings participants ascribed to their engagement in creative activities. However, Georgi (1988) and Sandelowsky (1993) point out that as the lived world is constantly changing, a particular concern in phenomenological research is the extent to which the results can be judged trustworthy. Moreover, the meanings that participants convey change from one interview to another. Therefore, although several interviews were conducted, it should be kept in mind that the findings of Study II (as well as the findings in the other studies) can primarily be considered as valid reflections of the participants' experiences, as communicated in a given time and context.

In Study I and II the participants talked about their creations as made from their own unique and individual ideas. However, from informal observations, during the interviews, it was clear that most of the creations made by the participants and other clients looked similar (i.e. had the same turquoise color). Therefore, it might be argued that had the interviews been combined with observations, aspects of sociality such as mutual inspiration among clients attending palliative OT could have emerged from the data. Such information might have added insight into other dimensions of sociality, expressed in actions not conveyed in the verbal interviews. This experience implies that

the informal observations conducted during interviewing could have provided valuable data if noted systematically from the beginning. Such information might have been useful in contextualizing the data (Tang Nielsen et al., 2006).

Participant observation was used as a method for ‘generating’ data in Study IV.

However, it could be questioned whether participant observation as conducted in Study IV, limited to a few hours per occasion and primarily focusing on certain activities, can be considered sufficient. According to Davies (2001) participant observation requires a long-term personal involvement with the people being studied, including participation in their lives, to the extent that the researcher comes to understand their culture as an insider. This was not the case in Study IV, but as noted earlier ethical concerns were also at stake and the choice to limit the level of participant observation in Study IV was due to ethical considerations and the wish to avoid intrusion or taking up too much time in this last period of the lives of participants. Instead it was decided to combine several methods of data collection, and the use of semi-structured diaries was chosen as an alternative entrance for exploring how people with advanced cancer create meaning and manages everyday life through engagement in activities. It is, however, possible that richer insights into the activities of everyday life, and processes of meaning-making, might have been gained by more extensive participant observation.

Triangulation

A combination of methods was used in Study III and IV. Collecting information by using a variety of methods is considered as a means of triangulation (Maxwell, 1996). Triangulation to achieve convergence is based on the idea that multiple perspectives for mutual confirmation of data ensure that multiple aspects of a phenomenon have been investigated (Maxwell, 1996). However, triangulation does not automatically increase the validity of findings in a given study (Coffey & Atkinson, 1996). In Study III the

Time Geographical Method, TGM, involved data being treated in a quantitative manner, by registering the frequency and duration of activities, as well as in a qualitative manner, by reading text from diaries and interviews. Giorgi (1992) has raised concerns about the validity of knowledge acquired by combining theoretical and methodological principles from different philosophies of science, which he refers to as mixed discourses. Thus, the question of whether mixed discourses influenced validity might be raised in relation to Study III. In that study the quantitative registrations provided descriptive knowledge about time-use and about the activities that occupied the day. This formed a template for understanding the qualitative information about how participants experienced and valued those activities. Therefore it could be argued, that the combination of methods worked together to illuminate the participants' subjective experiences of activities as well as the structural aspects used to organize activities in daily living such as which activities were performed, when, where, with whom, for how long periods of time and how often. Consequently, the triangulation in Study III might have provided data supporting the complexity of the results.

Study IV also applied a combination of methods using interviews and participant observations. For example, Study IV was based on analysis of narratives retrieved both as told and as enacted stories. When participants shared their stories orally, in conversation with the researcher, they might have been telling a story to convey favorable impressions. Such coloring of verbal stories by participants might be balanced by gathering stories as performed by participants in activity, which may reveal tacit aspects of meaning. Thus by combining methods and attending to both oral and performed stories, the validity of the participants narratives might be increased (Tang Nielsen et al., 2006).

Generalizability

In research there is often the desire to generalize results by making them applicable to larger populations than the group studied (Sandelowsky, 1993). The findings of the studies in this thesis are not generalizable in the sense of being representative of a larger population. However, qualitative research does not seek to be generalizable in terms of statistical representation but rather to increase depth and understanding of the subject of study in order to guide other situations (Kvale, 1996). The notion of applicability is useful for considering generalizability in qualitative research (Morse & Field, 1996). Applicability pertains to whether the findings of a given study can be applied in contexts outside the study situation, for example for analytical understanding of other people with advanced cancer in other contexts or situations, or with other people in other kinds of conditions (Kvale, 1996). One way to consider applicability is by juxtaposing the findings of the studies in this thesis with other research in the field, and to see if the findings resonate and make sense when presented in other contexts. Attempts to do so have been made with the results from each of the studies in this thesis. For example, by comparing the results of Study II with the results of other studies addressing related issues, such as in the study by S.R. Hansen (2003), who identified the typology of suffering, it became apparent that there are some resemblances in the findings of what the participants with advanced cancer experience. When similarities are found across several independent studies, this may be viewed as an indicator that the results are applicable to people with advanced cancer on a more general level (Morse & Field, 1996). However, evaluating applicability is an ongoing process involving the findings being compared and critically assessed by other communities of researchers and professionals in the field under investigation (Sandberg, 1995), and this is also true of the findings of studies in this thesis.

In conclusion, the findings of the studies in this thesis suggest ways in which to understand the potential of engagement in activities of people living with advanced cancer.

IMPLICATIONS

The implications of individual studies, and of particular aspects of the research underlying this thesis, have already been covered in the discussion. Despite the risk of repetition it is, however, worth dwelling, in conclusion, on some general implications that have particular relevance for clinical practice and for future knowledge development.

Processes of empowerment through engagement in activities

- The findings indicated that people with advanced cancer seek to create connections (Study I) and rhythms (Study III) that facilitate connectedness and continuance through their engagement in activities. These findings confirm that engagement in activities forges connections to life and to experiences of being alive. By this is meant both connections to the life that is currently being lived, inside or outside the context of treatment, and connections in a more abstract way, symbolized through the concrete creation of artefacts and embedded with experiences from life prior to illness and/or pointing towards life in the future that lies ahead, also after death. Therefore it is imperative that, when palliative occupational therapy and other forms of palliative care promote activities, they do so with an increased awareness of the need to support opportunities for creating connections in both verbal and non-verbal forms of activity.
- Processes that included *confronting* issues pertinent to the individual, *experimenting* with ways to address consequences of incurable illness and *acknowledging* priorities and capacities were identified as lived experiences of engagement in activities (Study II). These processes were found to empower the participants in addressing some of the pertinent issues they were facing as a

consequence of advanced cancer. Palliative care therapies, that use activities for intervention, may employ these findings to justify and utilize the processes that engagement in activities can facilitate. For example, confrontation with the debilitating aspects of advanced cancer, such as physical decline and stigmatization, implies that engagement in activity should not simply be viewed as a 'positive'. When used for intervention, activities must be based on a careful analysis of their risks as well as the potential that engagement can involve. Since activity-based palliative occupational therapy is not well-established throughout Scandinavian countries like Sweden and Denmark, the findings of Study I and II provide empirical validation of occupational palliative therapy as a service that by use of activity may empower people with advanced cancer.

- The findings from Study I and II also showed that participants disconnected from activities they could no longer undertake and from their previous ways of doing. This might have implications for clinical practice in developing services that not only build on previous interests and the activity history of patients and clients, but are also supportive of the explorative processes in activities that can open up avenues for renewed engagement.

Enabling complexities in social milieus

- The findings of Study I showed that a generous environment functioned as a space fostering engagement which was created through collaboration and the mutual investment of clients and therapists. Clinical practice may, therefore, benefit from paying due attention to the interaction and collaboration needed between clients/patients and therapists.

- Another aspect of social milieus with clinical implications, that emerged from the findings (Study I, & II), is that participants both had a desire to be with people in similar conditions as themselves and had concerns about excessive focus on the detrimental aspects of advanced cancer that could come from being with others in similar conditions. Therefore palliative care services that aim to facilitate social community and exchange, for people with advanced cancer, might benefit from ensuring that topics not only concern the detrimental aspects of illness, such as management of distressing symptoms like pain and fatigue, but also focus on enriching aspects of life.

Attention to rhythms of activity as a means to achieve satisfaction in daily living

- The construction of rhythms in daily life was identified (Study III) as being significant for the participants' sense of satisfaction. This underlines the necessity for health care services, for people with advanced cancer, to pay attention to the activity rhythms of their patients/clients to ensure that interventions provided are supportive of rhythms of activity that facilitate satisfaction in daily living. Furthermore, the findings on rhythms (Study III) included both objective and subjective aspects of activities. Such knowledge may be used in clinical practice by supporting rhythms based on attention to 1/ the structural aspects of rhythm (such as temporality, location and social context) as well as 2/ the experiential aspects such as personal predilections. Finally, the findings relating to rhythm may have implications for developing knowledge about human occupation by suggesting that rhythms of activity are composed of activities of routine and activities of change characterized by distinct values in a dynamic interplay.

Engagement and emplotment of activity enables multiplicity

- From the results of Study I and IV it became apparent that engagement, and the conduct of activities in therapeutic settings, as well as in everyday life, may function as a resource in constructing and reconstructing meaning when living with advanced cancer. For example, in being healthy although sick and in creating ‘Mecca’ as spaces for refuge. The fact that participants create several simultaneous ongoing narratives (Study IV) indicates that through engagement in activities they can move between a variety of possible understandings of their situation. This knowledge might be of value for clinical practice and palliative care by empowering patients/clients through opportunities for engagement in activity, to take on agency and handle complex situations when dealing with life-threatening illness.

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