

Thesis for doctoral degree (Ph.D.)
2008

EXISTENTIAL CHALLENGES AND COPING IN PALLIATIVE CANCER CARE

Experiences of patients and family members

Lisa Sand

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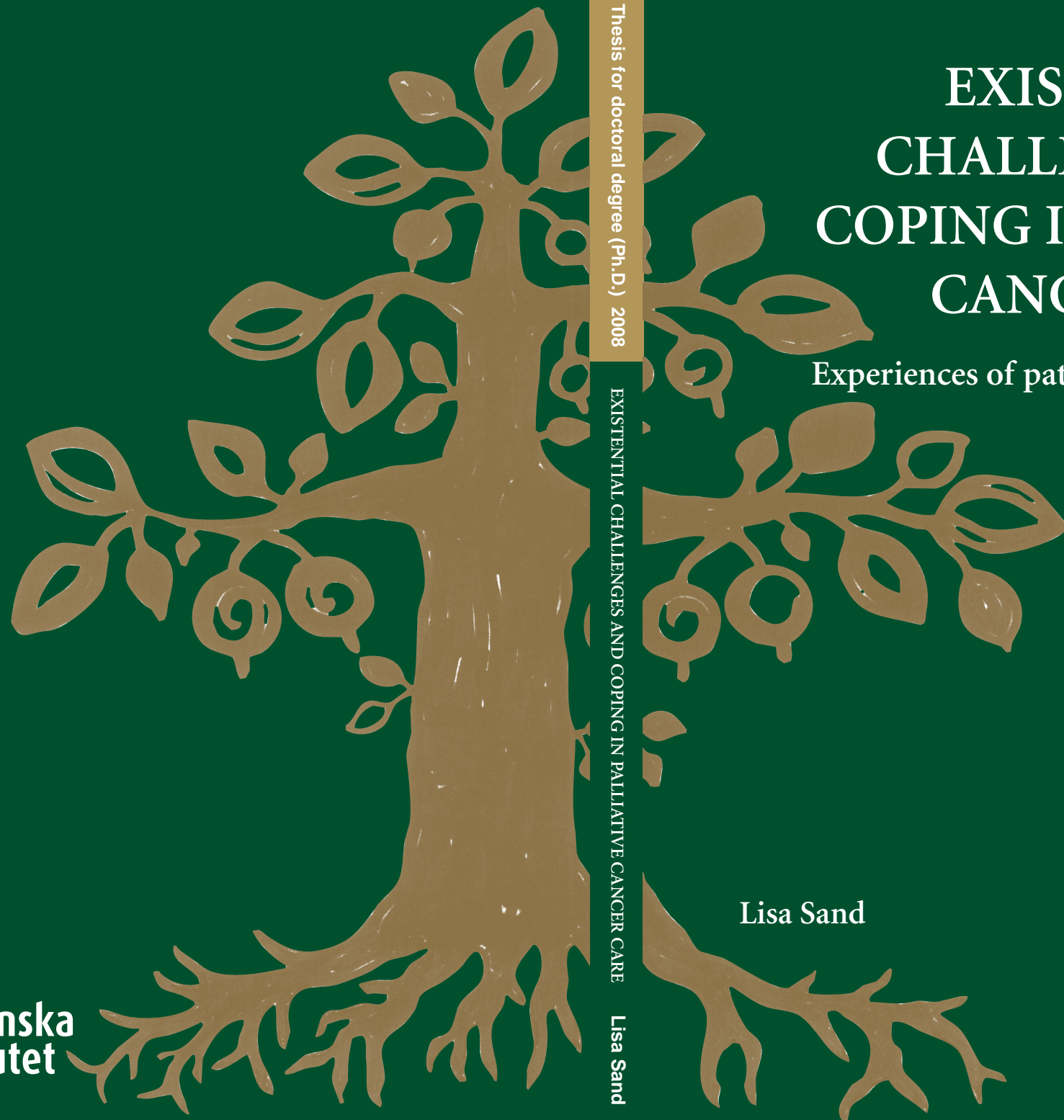
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ABSTRACT

The overall aim of this thesis was to gain knowledge about the existential crisis in patients and family members caused by an incurable cancer and how the crisis is managed.

Two methodological approaches were used. Semi-structured tape-recorded interviews (20 patients enrolled in palliative care and 20 family members) were analysed using hermeneutics. A postal questionnaire with open-ended questions was distributed and the responses (103 patients enrolled in palliative care) were analysed with qualitative content analysis.

In Study I patients' and family members' experiences of existential loneliness were investigated. The disease had brought changes to their day-to-day life and to the patients' bodies which had made them vulnerable and exposed as they were reminded of their mortality. It was the patient's impending demise that was the primary source for experiences of existential loneliness in both the patients and family members.

Patients' experiences of helplessness and powerlessness were investigated in Study II. Challenges caused by symptoms, loss of control and autonomy, of feeling ignored, lonely and uncertain constituted the basis for the experiences for helplessness and powerlessness. Those feelings were reinforced by the aspects of suddenness, high intensity and lengthiness which undermined the patients' coping skills.

In Study III family members outlined responsibility as a demanding task but also as a coping strategy. They had increasingly become aware that the disease was affecting their whole family. In the first place their responsibility had been to see to the patient's best. But their undertakings also included their own and other family members' well-being as well. By holding on to structures that supported life and meaning they mitigated the impact of harmful reminders of death and prevented meaninglessness from spreading.

The patients' shaping of useful coping strategies to restrain death (Study IV) could be symbolised as a cognitive and emotional pendulum, swinging between the extremes of life and death. They strived to find factors that could help them to keep death at a discreet distance and preserve their links to life. These links were togetherness, involvement, hope and continuation and they served as a shield against hurtful feelings connected to their impending death.

The impact of the physical body was evident in all four studies. Despite the fact that the body is usually not regarded as being an existential aspect, the results stress that human existence is ultimately based in the body. Both patients and family members had experienced that the patient's body had become a detector of life and death.

The results of this thesis illuminate the profound and inevitable impact of death-threat in a palliative context. Primarily it exerts influence on the patient but it affects family members as well.

LIST OF PUBLICATIONS

- I. **Sand, L., Strang, P.** Existential loneliness in a palliative home care setting. *Journal of Palliative Medicine*. 2006; 9 (6): 1376-1387.
- II. **Sand, L., Strang, P., Milberg, A.** Dying cancer patients' experiences of powerlessness and helplessness. *Journal of Supportive Care in Cancer*. 2008, Jul;16 (7): 853-62.
- III. **Sand, L., Olsson, M., Strang, P.** Inducements for taking responsibility. Family members in palliative care. (2008, submitted)
- IV. **Sand, L., Olsson, M., Strang, P.** Coping in the presence of own impending death from cancer. *Journal of Pain and Symptom Management*. (2008, in press)

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LIST OF ABBREVIATIONS

APHC	Advanced Palliative Home Care
EVS-studies	European Value Studies, initiated by The European Value Systems Study Group
SOM-reports	Reports from the Swedish SOM institute (Society, Opinion, Mass media) (Samhälle, Opinion, Massmedia)
WHO	World Health Organization

1 INTRODUCTION

INTRIGUED BY A QUESTION

Slightly more than thirty years ago I was a newly qualified social worker and substituted in a medical/surgical ward in a hospital in Stockholm. In those days the patients in the worst condition were placed in single rooms at the very end of the corridor, away from the staff office. At times the daily rounds passed by without entering those rooms at all. I perceived the patient's loneliness, the family members' unspoken questions and the staff's helplessness. I myself went through agony over my own shortcomings unable to contribute in any way. I did not manage either to support the patients, the family members or the staff. I was too young and too inexperienced. When I left that temporary job, I carried a question around with me which never really has left me since. The question was and still is: "What do people hold on to when they are faced with their own impending death?" That question has followed me all the years while I worked with people with AIDS and further on in to my employment as a social worker in palliative cancer care.

In palliative care the ambition is to support the patient not only physically but also psycho-socially and spiritually-existentially. This support should also include the patient's family. That is a worthy aim but also challenging. It provokes on answers to questions such as: What do we actually mean when we say that we provide spiritual and existential support? How should it be offered and what issues do patients and family members want to share? Despite the fact that today Sweden is a multi-cultural society, secularised native-born Swedish families still constitute a considerable part of palliative cancer care. What needs of spiritual and existential support do they have? When I originally posed these questions to colleagues and to myself I did not get any satisfactory answers. At that time, which was in the middle of the 1990s, I was not able to make any advanced searches for articles in data bases but when I tried, I did not find much at all. There were studies but they were performed abroad and consequently secularised native-born Swedes were not included among them. I was encouraged by others not to give up in my small investigation and to go on further with my questions. I did and now I have finished my thesis, a fact that still sometimes seems unreal to me since the idea of myself as a doctoral student had never crossed my mind previously. I must say it is amazing to note that despite the fact that the overall aim for the study is a bit extensive, it is still the single question that I have been carried with me for more than thirty years that constitutes the origin of my research. "What do people hold on to when they are confronted with their own impending death?"

2 BACKGROUND

2.1 DEATH AND HUMAN KIND

Death has always challenged human beings, it is difficult to explain and impossible to control. The ritual of placing artefacts in the grave indicates that the awareness of death and attempts to transcend it has challenged humans since time immemorial (1) p 143. This is independent of whether the purpose for putting them there was to prepare the deceased for another world, to prevent them from remaining in the world of the living or was just meant to ensure them a good send-off.

The inevitability of death is a terrible truth that people manage to hide from for most of their lives (2). The will to live and hold on to life is a strong force (3). Even a minimal chance of a longer life among patients with cancer is considered sufficient, to expose oneself to the risk of severe side effects from treatments (4).

The fact that death possibly implies unconditional annihilation has always been difficult for humans to accept. According to the American psychiatrist Robert Lifton “death and continuity of life is man’s oldest and most fundamental image for understanding human existence” (5) p.29. Even if there were proofs of the immortality of the soul, it would not remove the fear of death. Because existentially people are nevertheless aware of the complete loss of the body and the self that death implies (6).

In the urge to maintain an inner sense of immortality, the human capacity for symbolization has been highly useful in the creation of different modes of enduring life and meaning. The existing symbols of death are often dualistic and embrace the relationship between death and life (7, 8). Death is described as the end of something but also as a symbol for the birth of something new. To personify death is a way of making it concrete and easier to comprehend and this tendency is rather ancient (8). Also here the dualistic pattern is clear. Death could be pictured both as a frightening skeleton and a merciful angel.

Throughout history, societies have developed socially acceptable systems to deal with death (8). These systems have one thing in common in that they offer a sense of control. By giving a task to people who are concerned, they counteract the experiences of helplessness. They also neutralise experiences of loneliness through shared rituals and grieving, rooted in well-accepted collective belief systems and rituals. During different periods of time people have also turned to disciplines like religion, philosophy and medicine to find explanations in order to cope with the inevitable consequences of death.

To gain a better understanding of the varying attitudes in history to death and dying it is necessary to put them in a context. One way of doing this is to use ideal types (9). These ideal types are not ideal in a sense of desirable but they are formed from ideas inside a researcher’s head. They are aimed at identifying themes and tensions in order to identify complexities in the real world. The British sociologist Tony Walter (9) has traced the historical movement of death and presents three ideal types that could be contributing to an understanding of people’s attitudes to death over time.

Traditionally death was often caused by diseases that have been eradicated today or are now easy to cure. The death trajectory was fast; it was often children and young

people who died and death was ever-present, occupying a central place in the community. God, the church and traditions were the authorities over death and religion gave death a meaning.

In **modern** society, death was caused by cancer or coronary diseases. It was mostly elderly people who died; they did it in hospitals and the death trajectory was hidden away from others outside the nuclear family. The authority did not come from traditions any longer but from medical expertise. Outside the religion the meaning of death was dissolved.

According to Walter, people in **neo-modern** society distrust authorities. Death is caused by diseases such as cancer and AIDS. The death trajectory is prolonged and death has to a certain degree moved from the hospitals back to the patients' homes. The ultimate authority over death is the individual self and meaning is sought on an individual basis through family and friends and by means of secular or religious counselling. When the collective belief systems are weak the individual must create or invent her own sources of power.

2.2 EXISTENTIAL AWARENESS IN SWEDEN TODAY

2.2.1 Secularization

Historically, the Christian Church has had a large influence over people's lives in Sweden and offered a frame of reference surrounding death giving a sense of control and meaning. Within Christianity death is not only the end of something and it does not imply loneliness (9, 10). It is defined as a spiritual passage and the fate in the hereafter is strong (11). When you die you have to leave and go away but you will be met (10). Even if the plausibility of a traditional heaven and hell in bygone days was not only reassuring, it was an existing conception, an idea of order shared by the vast majority (8).

Today Sweden is secularized i.e. the relevance of a specific religion is waning both in society and individually (12). Even if 75% of the inhabitants still belong to the Swedish Lutheran Church, (13) they are not necessarily active Christians (14). Only 2,7 % of the inhabitants in Sweden regularly attend church (15). However, as indicated both by the European Values Study (14) and some of the SOM reports (16, 17) people in Sweden still tend to believe in some kind of spiritual power or life force. The fact that people leave the Church does not mean that they do not believe in anything. But their belief-system is more individual and private. People will believe what seems right to them, not what the church tells them. An inner quality may be furthered through a one-to-one dialogue with a personally created God or a higher power rather than shared in a congregation (10). The religious dogmas have been challenged by an individual and personal idea of order or faith.

Today each individual and each family have to create their own meaning in life and death. Relieved from the authority of traditions, they have to face the authority of the self which advocates a personal world-view, strong enough to offer comfort and support (3, 10, 11). To choose their own ways of coping with death implies a larger amount of freedom but also responsibility and loneliness.

2.2.2 Spirituality, religion and existential issues

There have been numerous efforts to define and to distinguish the concepts of spirituality and religion within the palliative care context in the western world (18-22).

An explicit definition of spirituality is lacking. It is not feasibly possible to reach a consensus, since the conceptions are open to too many connotations and personal meanings.

Within Christianity, spirituality is the heart, the very essence of religion (22, 23). It is the vehicle through which people encounter their calling and the deepest challenges, the mysteries of their own life and death.

Healthcare authors in Sweden today generally join in a view of spirituality being broader than religion (21). That broader sense of spirituality which is identified with the search for meaning, has more to do with the human spirit as the animating or vital principle in a person than anything to do with religion (24, 25). When we are challenged by existence and forced to face negative life events, for example a palliative cancer diagnosis, we try to explain and make sense of the occurrence (26-28). Otherwise there will be no control, no prediction and no feeling of safety and shelter. This is easier if we have a world-view, an idea of order which can help to make our existence comprehensible (26, 28, 29). This world-view can be religious or secular and a spiritual dimension can, but not necessarily, be present in both (20, 30-33).

Also the definition of existential issues varies. There is no single, commonly accepted definition but a general agreement must nevertheless be considered prevalent. The existential issues engage more than the emotional parts of a person. They belong to the human fundamental ground (3, 6, 34-36) and imply concerns that humans are unavoidably confronted with during their life. These concerns are:

Freedom, that involves responsibility and choices, and therefore also anxiety and guilt. "Freedom" to choose means that beneath us there is no solid ground. The existential dynamic is between groundlessness and own wish for ground and structure.

Existential loneliness, experiences that springs from the fact that humans are fundamentally alone. Each one of us must enter existence alone and depart from it alone. The existential tension is between our awareness of absolute isolation and our wish for contact.

Meaninglessness. From an existential philosophical point of view there is no preordained design for us. Nobody but one self is responsible for finding out what is meaningful to us. The existential dynamic conflict stems from the dilemma of being a meaning-seeking creature who is thrown into a universe that has no meaning.

Death, truly *the* ultimate concern. We exist now, but one day we will cease to be. It is a reality that we have to cope with. The core existential conflict is the tension between the awareness of the inevitability of death and the wish to continue to be.

In the thesis "Spiritual/existential issues in palliative care" (37) Susan Strang concludes that it is impossible to draw a dividing line between the different concepts. She tries instead to define which core features there are for each domain. She considers them elucidatory but they still do not eliminate the fact that the concepts partly overlap. (37) p.14.

Spirituality	Religion	Existentialism
Meaning	God	Freedom
Transcendence	Worship	Isolation
Higher power/ source of energy	Rituals	Meaning/meaninglessness
Relationship	Social manifestation	Death
Religious dimension		

2.3 EXISTENTIAL CRISIS

When a person finds herself in a situation where earlier experiences and learned ways of reacting prove insufficient to comprehend and cope with the situation, she finds herself in a psychological crisis. (38) p.12. Within existential psychology, crises are looked upon as something natural that belongs to human existence (39, 40). They are regarded as always being existential since they inevitably affect the lives and the existence of the persons' involved. Crises associated with an incurable cancer are definitely existential. The patients' life is threatened and so is also the family member's fundament and future. This is a boundary situation (3, 39, 41) that propels people into a confrontation with existence. Such a disease challenges all those involved to cope with profound existential questions about unpredictability, responsibility, guilt and meaning.

2.4 DEATH ANXIETY

A wide spectrum of factors can generate anxiety in palliative care. Besides a fear of death and the existential anxiety that is provoked (3, 10) there are also physical factors such as uncontrolled pain, dyspnoea, abnormal metabolic states, pulmonary emboli and hormone-producing tumours that can cause anxiety (42).

There is no existing consensus about what exactly constitutes death anxiety and what people are actually afraid of when they fear death (8, 43). It has been suggested that death anxiety is a composite of different distressing factors and smaller fears (8, 44): suffering, separation anxiety, fear of disability, dependency and loneliness, of the dying process, of ceasing to exist and about what comes after death were the fear of personal extinction seems to be at the vortex of concern (3).

Fear and anxiety are two different notions. When making a comparison between them, fear has a clear object, anxiety has none. Anxiety is consequently linked to uncertainty, often leading to insecurity. Rollo May also states that fear and anxiety represent threats to different levels in the personality. He proposes a link between anxiety and threat to our basic values, the core or "inner citadel" (45) p. 225, of the personality.

From an existential perspective, death anxiety has been described as a reaction to the constant threat from an ontological non-being (6, 35) or from nothingness (46), states which are impossible to conceptualise and therefore challenging to cope with.

Because individuals conceptualise death differently and also place different meanings on it both for themselves and their families, it is perhaps impossible to reach a consensus about what death anxiety exactly is. One thing that there still is a consensus around is the fact that *fear* of death does exist (47) and gives rise to distress and suffering.

2.5 PALLIATIVE CARE

Palliative care has its roots in the modern hospice movement, beginning in the 1960s (48) when Dame Cicely Saunders opened St Christopher's Hospice in London with the

aim to improve dying patients life necessities. In the context of the increasingly impersonal nature of modern technological medicine, the core element was an emphasis on the personal (49, 50). As Cicely Saunders expresses it, it “grew from opportunities to listen to patients and to pay attention both to their needs and their achievements” (48) p.1. Palliative care is an active total care of patients whose disease does not respond to curative treatment (51). Relieving different kinds of distressing symptoms is paramount, physical as well as psychosocial, spiritual and existential. Both the patient and her family constitute the unit of the care and the family members are to be offered help to cope during the patient’s illness and during their own bereavement.

In Sweden, professor Barbro Beck-Friis was the pioneer, by introducing hospital-based home-care around the clock for palliative cancer patients (52). Today a considerable part of the palliative cancer care is delivered from advanced palliative home care units that operate with a multi-professional team on a 24-hour basis, with access to a back-up ward (53).

3 THEORETICAL FRAMEWORK

3.1 EXISTENTIAL PHILOSOPHY

The existential tradition is ageless. There are reasons to assume that as long as there have been humans on the planet, they have been challenged by existence and they have posed questions about life and death. In fact “The Gilgamesh Epic” (54), about 4000 years old and one of the oldest known written documents, is an existential drama about meaning and the acceptance of death. During antiquity, philosophers such as Socrates and Aristotle (55, 56) addressed the question of what it means to be a human being.

The beginning of the modern existential philosophy movement, Existentialism, is usually associated with the work of Søren Kierkegaard and the middle of the nineteenth century (57). After a chain of dramatic events in Kierkegaard’s private life, he devoted himself to exploring his own existential situation. He published several important books and treatises and his work was later, together with those of Aristotle important sources of inspiration for i.e. Martin Heidegger (35), Paul Tillich (6) Jean Paul Sartre (58) and Victor Frankl (59). Although approaching the existential questions from different perspectives, the existential philosophers have a common question they address, namely what it means to be a human being and how humans can find or create meaning given the realities of life and death (60).

The existential philosophic view on death involves the specific significance that the idea of death takes on for a human (2, 6, 7, 35, 36). The experience of an existence progressing towards death is a human basic given that humans have to relate to. The awareness of one’s personal death can be dreadful but it is also a spur to remain mindful of being (2, 35). It is the exposure to the threat of losing fundamental and precious values, the state of “being towards death” (35) that forces us to become conscious of life’s full meaning and making the most of the moments given (3, 35, 36, 45, 61). Despite this outlook on the *idea* of death as a spurring factor within existential philosophy there are also an awareness of that the confrontation with one’s own mortality can be a boarder situation that can end up in rumination and despair (41).

3.2 EXISTENTIAL PSYCHOLOGY

The existential philosophy is the ancestral home of the existential psychology (3). I have chosen existential psychology as the theoretical frame for this thesis because of its focus on existential challenges in people’s life and understanding of how these challenges might be managed. Existential psychology started as a loosely defined movement in Europe and USA during the 1950s and 1960s. It was initially a reaction to the predominantly Freudian theory about forces in conflict within the individual as a fundamental cause of concern (3, 36, 60). Psychiatrists and psychologists such as Viktor Frankl (59), Robert Jay Lifton (5), Rollo May (36) and Irvin Yalom (3) argued the importance of basing an analysis of human behaviour and human emotions on the subject’s own reality, in the world where she lives and has her being. Irving Yalom writes in his book “Existential Psychotherapy”: “The existential position emphasizes a different kind of basic conflict (than the Freudian): neither a conflict with suppressed instinctual strivings nor with internalized significant adults, but instead a conflict that flows from the individual’s confrontation with the givens of existence” (3) p.8. By “givens of existence” Yalom is referring to concerns that are an inescapable part of the human being’s existence in the world and that exert enormous influence on people’s

lives. The concerns Yalom delineates are freedom, existential isolation, meaninglessness and death. As a human being it is inevitable to be challenged by them during the course of one's life. One of the core issues of existential psychology is how humans fashion a world of meaning in a reality that includes both inevitable threats and despair (62).

3.3 VIKTOR FRANKL'S CONTRIBUTION TO EXISTENTIAL PSYCHOLOGY

Viktor Frankl is the founder of Logotherapy which is an existential therapy as well as a philosophy (63) where meaning (logos=meaning) and responsibility are essential. According to Frankl, meaning is a primary instinct in human beings and the need for meaning is a primary motivation force in people (34, 59). A life that is characterized by feelings of meaninglessness causes despair and existential suffering.

It is often wrongly said that Frankl developed his logotherapy when he was in a concentration camp during the Second World War. In fact his ideas were well systematized before this. It was the everyday clinical experiences as a psychiatrist that inspired him to develop his logotherapy instead of the experiences from concentration camp. A sense of meaninglessness and emptiness, a condition that Frankl termed "Existential vacuum" (59) was a profound problem for many patients that Frankl and his colleagues met. During his years in the camp he was offered great opportunities to really try out his theories and check whether or not they were valid.

According to Frankl the meaning in life is individual and highly personal. It must be conceived in terms of the specific meaning of a personal life in a given situation (59). Subsequently, there is no one kind of all-embracing meaning, valid forever, or for everyone. It is something that is constantly present, waiting to be discovered, and it is consequently not something that ought to be created; the task is to discover it. In this respect his convictions differ from the construct of meaninglessness e.g. described by Heidegger who thought that there is no inherent meaning in life and therefore people have to invent one.

Humans are guided in their search for meaning by conscience. "Conscience", Frankl writes "could be defined as the intuitive capacity of man to find out the meaning of a situation" (59) p.63. During life, individuals are confronted with different kind of challenges that give rise to inner questions which call for answers. In such situations it is essential to be sensitive to one's conscience and make responsible decisions on the basis of what conscience commands. By giving responsible answers when responding to the questions that life poses, we create requirements to discover what is meaningful to us, Viktor Frankl stated. Within Logotherapy responsibility is consequently seen as the fundament for meaning (59).

Viktor Frankl suggested three basic values, that constitute the foundations, sources from where meaning emanates (34, 59).

Creative values are all the things we give to others or to the world our deeds and work of course, but also time, attention and love that we give to others. Fulfilled goals, even small ones are often experienced as meaningful and so is sharing experiences and skills.

Experiencing values is what we receive from others or from the world. This second source of meaning concerns the actualization of valued experiences or encounters that,

besides enjoyment, can give a sense of connectedness and also continuity. A primary example is the experience of love from others.

Finally, **attitudinal values**, are about the stand we take in a difficult situation that is impossible to change. Humans are not spared facing their human condition which includes challenges such as pain, guilt and death. But through the human ability to transcend oneself we are given an opportunity to fulfill meaning by choosing attitudes and taking a stand. Frankl underlines the fact that self-transcendence is the essence of human existence (64), a capacity as well as a quality.

3.4 COPING

The term coping implies the significance of the human capacity to use thoughts and behaviours to handle externally and internally taxing demands in a way that makes them possible to manage (27). The coping theory is developed with the aim of understanding how people handle taxing demands to be able to continue their lives. Coping is a multidimensional emotional and cognitive process that is sensitive both to the environment and to personality dispositions (65). It was Richard Lazarus (66) who in 1966 extended the significance of coping. Previously, it was focused on psychodynamic defence mechanisms and had an emphasis on pathology. Now it came to include a wide range of cognitive and behavioural responses that ordinary people use to handle distress in their daily lives.

More than twenty years ago Richard Lazarus and Susan Folkman (27) presented their stress-appraisal-coping model. In that model, the authors stressed the significance of how a demand is appraised. There are two main evaluative steps in the appraisal process: to gain an understanding of what is going on (the primary appraisal) and of what can be done (the secondary appraisal). The coping process is initiated only if important values are threatened, harmed or lost and the purpose of coping is not to master but to manage a demanding situation (27).

Lazarus and Folkman (27) draw a distinction between problem-focused coping and emotion-focused coping. The former is directed at managing the problem causing the distress while the latter is directed at regulating the emotional response to the problem.

3.4.1 Meaning-based coping

The significance of meaning-making as part of the coping process has been elucidated by several researchers (29, 67-70). When confronted with negative life events people strive to find factors that can help them determine personal significance of the experience in relation to the individual's values, goals or commitments (29, 71, 72). If people fail to resolve a dilemma through problem- or emotion-based coping strategies they may take advantage of meaning-based manoeuvres to reappraise their circumstances in order to achieve a better fit with their worldview (71) or to alter that view to accommodate the situation. In order to find meaning people also take advantage of their capacity of creating opportunities for positive events and infusing ordinary occurrences with positive meaning (71, 72). Human being's conceptual system is not always easily expressed in every day life but in the confrontation with life challenges it is indirectly displayed and used in the coping process to support their inner balance and structure (26, 29, 70).

4 AIM

4.1 GENERAL AIM OF THE THESIS

The overall aim of this thesis was to obtain knowledge about the existential crisis in patients and family members caused by an incurable cancer disease and how the crisis is managed. As already described in the background, many native born Swedish people are secularised today and it was considered important to investigate their experiences specifically. This group was targeted in Papers I, III and IV, respectively.

4.2 SPECIFIC AIMS OF THE PAPERS

4.2.1 Existential challenges (Papers I, II and III)

To gain a deeper understanding of some of the existential challenges that patients and family members are confronted with by an incurable cancer.

4.2.1.1 Paper I

Explore experiences of existential loneliness in patients and family members in palliative care, the origin of these feelings and their interactions.

4.2.1.2 Paper II

Illuminate the perceptions, experience and significance of powerlessness and helplessness in patients, explore factors that trigger the experiences and make descriptive quantifications.

4.2.1.3 Paper III

Investigate family members' inducements for taking and maintaining responsibility.

4.2.2 Coping strategies (Paper IV)

To obtain knowledge about coping strategies, that native born Swedish patients with cancer, who define themselves as non-religious, develop in the presence of their own impending death. To investigate how the patients reflect and act when they develop coping strategies and gain understanding of how these strategies are useful.

5 MATERIAL AND METHOD

The designs of the studies were cross-sectional and based on individual in-depth interviews (Studies I, III and IV) and on a questionnaire (Study II)

5.1 SETTINGS

5.1.1 Studies I, III and IV

These studies were conducted in a Swedish, advanced palliative home care unit (APHC) in the Stockholm area, with a capacity of 80 patients in their own homes on a 24-hour basis, run by a multi-professional team, and with access to a back-up ward.

5.1.2 Study II

The study population was recruited from four advanced palliative home care units (APHC) in two different Swedish counties. The four units had a multi-professional team, 24-hour services, and access to a back-up ward.

Table 1. Overview of the papers

Paper	Aim	Setting	Participants	Data collection	Method of analysis
I. Existential loneliness in a palliative home care setting	Explore this experience of existential loneliness, the origin of these feelings and their interaction	APHC-unit in the Stockholm area	20 patients 20 family members Non-religious	Interviews	Hermeneutics
II. Dying patients experiences of powerlessness and helplessness	Illuminate the perceptions, experience and significance of powerlessness, to explore factors that trigger the experiences and to make descriptive quantifications	Four APHC-units in two Swedish counties	103 patients	Questionnaires	Content analysis
III. Inducements for taking responsibility- Family members in palliative cancer care	Investigate family member's inducements for taking responsibility.	APHC-unit in the Stockholm area	20 family members Non-religious	Interviews	Hermeneutics
IV. Coping strategies in the presence of one's own impending death from cancer	Obtain knowledge about how native-born Swedes, who define themselves as non-religious, develop coping strategies in the presence of their own impending death from cancer and how these strategies serve their purpose	APHC-unit in the Stockholm area	20 patients Non-religious	Interviews	Hermeneutics

5.2 PARTICIPANTS

5.2.1 Studies I, III and IV

The study targeted patients diagnosed with an incurable cancer and some of their family members. They were all native-born Swedes and defined themselves as non-religious. In total 40 informants, 20 patients and 20 family members were interviewed in depth. Study I is based on all the interviews, Study III on the ones that were conducted with the family members and Study IV on those performed with the patients.

The patients were recruited applying a maximum variation sampling aiming at capturing and describing central themes that cut across variations (73). It was considered important for the study that variation was based on gender, age, family situation, occupation, diagnosis, total time of illness and the phase of illness. Data were collected between May 2003 and January 2005.

An overview of the characteristics of the informants is presented in Table 2 and 3.

Total number of patients	20
Sex (male/female)	8/12
<i>Age</i>	
< 49	2
50 – 69	11
70 – 89	6
≥ 90	1
<i>Marital status</i>	
Married/cohabits	12
Single/widow/widower	8
<i>Professions</i>	
Blue-collar workers	7
Civil servants	8
Self-employment	3
Other	2
<i>Primary malignancy</i>	
Urological	4
Gastrointestinal	3
Haematological	3
Lung	3
Breast	3
Brain	2
Gynaecological	2
<i>Time from interview to death (months)</i>	
0 - 3	11
4 - 6	3
7 - 9	4
>10	2

Total number of next-of-kin	20
Sex (male/female)	8/12
<i>Age</i>	
Total age range	16-79
<i>Relationship to the patient</i>	
Married	12
- Since less than 10 years	2
- Since 20 years and more	10
Child	6
Parent	1
Sibling	1
Employed	15

5.2.2 Study II

In total, 103 patients completed the questionnaire, response rate 58%. The study targeted adult, Swedish-speaking patients diagnosed with an incurable cancer, enrolled in palliative care. Data was collected between May 2004 and February 2005.

An overview of the characteristics of the informants is presented in Table 4.

Table 4. Patient characteristics
(Study II)

Sex (male/female)	43/60
Age in years (medium (range))	67 (40 – 91)
Married or cohabiting	77
Living alone	26
Type of malignancy:	
Gastrointestinal	21
Urological	19
Lung	12
Breast	12
Gynaecological	8
Other or unknown	31
Time since diagnosis (n):	
0 – 3 months	5
3 – 12 months	31
> 1 year	66
No response	1

5.3 DATA COLLECTION

5.3.1 Construction of the interview guide and the questionnaire

Since the interview guide as well as the questionnaire were weighty tools in the study, considerable efforts were put into creating them. The interview guide was constructed mainly by the first author and the questionnaire by all authors involved. They were thoroughly discussed with experienced staff in palliative care and piloted with patients, and the interview guide with family members as well. The aim with this pre-testing was to identify words or questions that were difficult to comprehend. During this procedure a modified form of think-aloud was applied (74, 75). This is a technique mainly used in cognitive interviewing when pre testing questionnaires.

5.3.1.1 The interview guide

The interview guide consisted of open-ended questions to encourage participants' spontaneous accounts. It provided a framework (73) within which the interviewer could be free to shape the conversation in interaction with the informant, deepen and validate the answer (76) but with focus still on the intention of the interview. As the aim of the study was to investigate the existential crisis, it was necessary to pose questions about existential issues and still use easy-to-understand, uncomplicated words.

From her long clinical experience as a social worker, the first author had learned that the use of words that have a religious tinge could result in people being on their guard. When the semi-structured interview guide was constructed efforts were therefore made to find words appropriate to a dialogue concerning existential questions but free from religious nuances. Some examples of questions that were posed are "Is there anything that seems more important now, compared with when you/your family member were healthy?", "Where do you get your courage and strength from?", "Where do you seek consolation?", "Can you tell me about something that really matters to you?" The same guide was used in all the interviews.

The interview guide is presented in Appendix 1.

5.3.1.2 The questionnaire

The questionnaire had both a qualitative and a quantitative part. The quantitative part consisted of questions concerning background data on the patient, his/her overall assessment of the support from APHC (5-grade Likert type; from 'Very bad' to 'Very good'), and frequency of feelings of powerlessness and/or helplessness during the APHC period (5-grade Likert-type; from 'every day' to 'never').

The qualitative part consisted of open-ended questions asking the patients to describe their experiences of powerlessness and/or helplessness in their own words, and to provide a concrete example of a typical situation.

The overall design of the open-ended questions was inspired by a qualitative interview technique (77) whereby the informants are asked to share a concrete situation in which they have experienced the phenomenon under study. The patients' descriptions of their experiences were guided by open-ended questions such as "What do powerlessness and helplessness mean to you?"; "Would you like to describe a situation in which you have experienced powerlessness and/or helplessness?" and "How did you manage the situation?"

The Questionnaire is presented in Appendix 2.

5.4 RECRUITMENT

5.4.1 For study I, III and IV

When recruiting an informant the initial contact was always made with the enrolled patient. Someone from the home care staff initially informed him or her about the study. After receiving permission, the first author made a telephone call and gave the patient some brief information about the study. If the patient was interested, a formal information letter was sent. The text in the letter was formulated to address both patients and family members. About a week later the first author called again. This contact either resulted in a patient declining to participate, a positive response from one or in some cases two members in the family, a request for further information or a desire to think it over once again. In the last case, the informant was asked to give his or her answer either by mail, by telephone or to any of the members in the home care team. Further information was provided by telephone or in a personal meeting with the interviewer.

The first author interviewed the informants on one occasion. The interviews lasted between 45 and 105 minutes. They were tape-recorded and transcribed verbatim, mainly by the first author.

5.4.2 For Study II

The patients were identified through existing clinical databases and were mailed the questionnaires together with an information letter. A reminder was sent after two to four weeks.

5.5 METHODS

5.5.1 Hermeneutics, used in study I, III and IV

The data was analysed by using existential hermeneutics (35, 78). Hermeneutics has its roots in Antiquity when it was started as a way of interpreting statements and texts (79). Over the centuries it has been used in analysis of human experience and social and cultural contexts. Originally, it was Heidegger who ontologised the hermeneutic approach through his book "Being and Time" (35, 80) where his aim was to reach an understanding of the existential meaning-structures of being-in-the-world (35), (chapter 2) and (80). He wanted to obtain knowledge about how humans strive to orient and find their way in a world they have been thrown into without their consent. In "Being and Time" he used hermeneutics to investigate and interpret different modes of what it means to exist.

Heidegger's analysis resulted in an insight that the systematic use of understanding and interpretation is not just a method of reaching understanding about texts; they are also foundational modes of man's being (35), (chapter 5 p.144). It is through understanding people orientate themselves and relate to others as well as to the world. If they do not understand they interpret to gain understanding.

The human process of interpretation is circular. It starts in the well known and continues as a tacking procedure between what is not understood and goes back to sources that eventually can contribute to a deepened understanding e.g. foreknowledge, other people

or other texts. A renewed reflection about the phenomenon that is under investigation has its onset in a new standard of attainment that has been created. This process is repeated again and again until an understanding has been reached. The hermeneutic circle is consequently not just a part of a research method. (35),(Chapter 5 p 153). It is also a structure of understanding as such and consequently a basic human model to gain understanding about existence and about one self. According to Heidegger, hermeneutics is both a method used to analyse texts and human experiences, and a philosophy about the ontological dimension of understanding (79) p.42. Some authors prefer the word spiral to the word circle, as the back and forth movements between parts and the whole are not circular on the same level, but should result in an understanding on a higher level.

The hermeneutic analysis is a process of deciphering. It goes from a manifest content and meaning to a meaning that could be hidden in the text (77, 79, 81, 82). The inquiry has no formally described method. There is no “hands-on” or “step-by-step” manual for the “process of deciphering”, but there are principles that are helpful during an analysis and they have been used here. They are originally described by Radnitzky (83) and later on adapted and extended by Kvale. These principles are: 1) A back-and-forth process between the parts and the whole, the hermeneutic circle or spiral. 2) Interpretation ends when a “good gestalt” is reached, an inner unity of the text, free from logical contradictions. 3) Testing the partial interpretations against the global meaning of the text. 4) Autonomy of the text, i.e. the text should also be understood on the basis of its own frame of reference. 5) Hermeneutical explication of a text concerns knowledge about the theme of the text. 6) An interpretation of a text is not without presupposition. 7) Every interpretation involves innovation and creativity.

Hans-Georg Gadamer and Paul Ricoeur are two modern hermeneutists whose work have been used in this thesis. Their focus of attention was not the same and they also had partly divergent thoughts about how understanding is to be reached. Hans-Georg Gadamer was the one who developed Heidegger’s existential hermeneutics and brought it further into the twentieth century (78). He attached a great importance to language in the human process of understanding. According to him, hermeneutics is an understanding of the human existence gained and conveyed through language (78), (Chapter 5), (82). Gadamer considered that the process of understanding was decided on an agreement about a matter at issue. He stated that we can only understand another person’s situation if we approach her world (78). He used the metaphor “fusion of horizons” (78) p.154 to illustrate this, where horizon is to be understood as a person’s way of comprehending her existence.

According to Paul Ricoeur, understanding is to be found in discrepancies rather than in agreements (84, 85). His focus was an interpretation of texts or other human manifestations of life that can be transferred as text (82, 86). He thought that the process of analysis must involve an alternating attitude from the interpreter between closeness and distance. The interpreter ought to be near the text and look behind the words but it is also necessary to take a step back from it and get some distance to it. Ricoeur considered texts as being autonomous and that they must have the chance to be treated as independent from context when they are being analysed. According to Ricoeur elucidating disparities through posing critical questions was an essential part of the interpretation process (84, 85).

In this thesis the aim was to obtain a deeper understanding of the meaning and implicit issues of what was expressed by the informants during the interviews. Therefore an *existential* hermeneutic approach was used.

5.5.1.1 *The overall process of analysis*

Initially I just read through the transcribed interviews several times without no other intentions than to get an overview of the text and an intuitive understanding of the informant's expressions (naïve reading). In the second step I read more carefully and exerted myself to be sensitive to what the text told me about the existential crisis caused by the incurable cancer and how the crisis is managed by the informants which is the overall aim of this thesis. I marked parts, sentences and even single words that seemed to be of interest. In the next step I scrutinised the units, and this time with a focus on the potential underlying meaning. Thus far the work was performed by me. The suggested meaning units were then the subject of joint discussion and interpretation by all the authors.

The hermeneutical process of analysing is a process where it is necessary to be highly sensitive in relation to the underlying meaning in a text i.e. parts that are not immediately understandable. It has been described as a process of posing open questions to a text (78, 82) and then follow the direction of the thoughts revealed through the text (85) p.60, or to interpret in the direction of the track (87) p.83. The interpretations raised were continuously called into question and other options were discussed. For example in Study I, the informant's experiences were discussed with the possibility in mind that other factors than existential loneliness could explain their spoken words. Could it be anger, sorrow or fatigue for example? When needed, extensive parts of the transcriptions were condensed (76) and in order to focus on the core information as well as to elucidate this, the text was abstracted.

During this procedure the statements were tested against other parts of the interview and the whole interview to see whether they fitted in there. In the process of analysis, alternative interpretations of the parts in an interview were tested and compared, by means of juxtapositioning (88). The procedure of comparing the parts with the whole was repeated several times, according to the hermeneutic spiral (82, 83).

The hermeneutic circle is not only confined to a comparison of the parts with the whole in the text. The circular and tacking procedure takes place between other factors that could be important to take into consideration as well. To switch over focus between clinically and theoretically grounded knowledge is such a factor. Another is to reflect over the researchers' pre-understanding and the context in which the interviews were conducted.

When using existential hermeneutic it is essential to obtain an understanding of how the informants conceptualise their world. To accomplish this task the first step is to reconstruct the informants' life necessities and the second is to look at these necessities from the informants' point of view. Not to see the world with the informants' eyes, as that is only possible for her or him, but to try to see the same things as the informant does (89). To be able to succeed in this, it is necessary to getting really close to the text (78). To minimise the risk of losing the perspective from "the whole" it is also important to take a step back and look at the text from a distance (85).

Finally the most plausible inherent meaning was compared with the entire text in order to test the interpretation. The analysis was concluded when the interpretation seemed coherent without any logical contradictions (78) p.137. This is normally referred to as a “good gestalt” in hermeneutic analysis. The results are presented both as “parts” and “as a whole” where “the whole” represents a synthesis of the categories at a higher abstraction level.

5.5.1.2 The overall process of analysing resulted in Studies I, III and IV

The general aim of the thesis was to gain knowledge about the existential crisis in patients and family members caused by an incurable cancer and how the crisis is managed. This was consequently my initial focus for the analysis. Studying loneliness (Study I) was not my intention from the start but early on in the process of analysing the interviews, the theme of loneliness faded in. The first time I become aware of it was when the informants expressed difficulties in reaching out to others and sharing their experiences of the cancer with them. When I continued my analysis of the interviews, and treated the text in accordance with the hermeneutical principle of posing open questions to the text and carefully listening to the answers, I noticed that loneliness was a phenomenon that appeared repeatedly. It manifested itself and called for investigation.

Almost the same course of events is behind the choice of focus in Study III. During the initial analysis of the interviews performed with family members, responsibility was outlined as a most demanding task. They described it with contradictory feelings. They emphasised that they took the responsibility out of their own free will but they also described the fact that it could cause them a lot of concerns and put them in an exposed position. A literature search made it clear that a number of studies have shown *that* the family members in palliative care despite all the burdens take their responsibility. However their inducement for doing so has not been elucidated very much. A prerequisite for understanding of the family members’ situation in palliative care is also some knowledge of this. Therefore I decided to delve further into this area.

5.5.1.3 Pre-understanding

According to hermeneutics, interpretations without presuppositions are impossible. In addition an explanation of a text concerns knowledge of the theme in the text. As an interpreter it is important to be aware of one’s own pre-understanding to minimise the risk of unconscious influence of the analysis. Therefore, the interpretation is made from a given perspective or theoretical framework. This should be stated, in order to give the reader a tool to be able to form an opinion of the dependability (90) of the analysis. Concerning my own pre-understanding it has been shaped during my work as a social worker. I have worked for ten years with HIV-infected people and their families, as well as ten years in a palliative home care setting. Consequently, I have a long experience of encounters with dying patients and their families. Of course this could serve as a facilitating factor but also as a hindrance to genuinely being open-minded to unusual and unexpected results during the analysis. The pre-understandings run the risk of being influenced by prejudices (78) p.146 especially when all the people involved in the process of analysis are engaged in the same medical discipline. In such a situation it is of great importance to take advantages of what Paul Ricoeur thought about the value of discrepancies in an interpretation, (84, 85). During the process of analysis alternative options were therefore continuously and thoroughly tested.

5.5.2 Content analysis, used in study II

When analysing the responses to the open-ended questions in the questionnaires, a qualitative content analysis with no predefined codes, were used (91-93). A central idea in content analysis is that words inherent in a text can be classified into content categories and that this gives the researcher an overview of what is really being expressed (93). Initially the method was used to count the number of words and to make quantitative descriptions of a manifest content in different kinds of communication (92). Over time it has been expanded to also include interpretations to examine an inferred or latent meaning of communication (92). When using it the aim can be to create final qualitative categories. But it can also be used to count occurrences within given categories that initially have been created during an inductive analysis. The applicability of qualitative content analysis as an analysis method for open-ended questions in questionnaires has been described previously (94).

The analysis of Study II was performed using the following steps: Firstly, all the responses were read through several times to obtain a sense of the whole. Secondly, the responses were reread systematically, line by line, to identify significant text segments, i.e. "meaning units" and to develop matching codes. The answers marked with similar codes were brought together and formed preliminary categories. As far as possible the actual words written by patients were used. Thirdly, the statements in each preliminary category were scrutinised and compared to find their central component and were fused into categories. Fourthly, the final categories were compared to avoid obvious overlapping, and content descriptions as well as relationships with other categories were developed.

From the start, the text material was analysed with a manifest focus, i.e. a descriptive analysis staying close to the text and the informants' own choice of words (91, 92), These results are presented as categories related to "Triggering factors" and "Aggravating circumstances".

As the data was considered to be rich enough with several detailed stories of episodes, we extended the study by a qualitative content analysis with a latent focus i.e. an interpretation of the underlying meaning of the text (91, 92). These results are presented as categories related to Existential meaning. Quotations were used to exemplify the categories.

The responses to the quantitative part of the questionnaire were summarised with descriptive statistics.

Table 5. Examples of meaning units, codes and categories

Meaning unit	Condensed meaning unit	Code	Category Manifest	Category Latent
<i>[I had a]” traumatic reception at the hospital. First [I heard] ‘fatal disease, then ‘perhaps operable’ but ‘the most complicated one we do here’. Such information creates anxiety, worry and feelings of helplessness. Then ‘you’ll maybe live until Easter without an operation – powerlessness.”</i>	I was scared and I could do nothing to change the situation	Symptoms (of cancer)	Helplessness and powerlessness caused by serious information about the disease	Powerlessness caused by a confrontation with a death-threat

5.5.3 Trustworthiness

During the interviews (Papers I, III and IV) dialogical validation was applied (76). Similar questions were posed several times during the interview but expressed differently. Together with follow-up questions like “Have I understood you correctly if I understand your answer as....?” this is a way of ensuring the genuine expression of the informant (77).

Dialogical intersubjectivity (76, 88) was used in the analysis of all the papers where the researchers analysed the interviews separately. At least two researchers were involved in the analysis of each paper. The first author mainly did the coding and development of the parts (Studies I, III and IV) and the categories (Study II) and the co-authors concentrated on reviewing the findings. In case of any discrepancies, these were discussed and common descriptions were formulated. The aim of the discussions was not to reach consensus, but to broaden and find possible alternative interpretations (95). Involving several researchers is a way of reducing the risk of investigator bias, by researchers supplementing and contesting each other’s readings, corresponding to reflexivity (88). In addition this study involved researchers representing both genders as well as different professional backgrounds and preconceptions.

To further strengthen the validity, peer debriefings were conducted and all the papers have been presented and discussed in research seminars involving clinically experienced nurses and social workers, PhD-students and senior palliative researchers.

5.5.4 Ethical considerations

The respective ethics committees have approved all four papers in this thesis.

Research in palliative care includes people who are in a vulnerable situation due to serious diseases and limited life expectancy. These facts have occasionally give raise to a discussion about the appropriateness of doing research in this area. Since there is an urgent need to gain knowledge about what good palliative care is and how it should be provided, it is necessary to carry out research in this field as well (96). However, the circumstances to hand highlight the importance of putting the existing ethical rules into practice and of letting the ethical consideration be a part of the research routines. There are general binding rules and regulations that apply to all research in medical care.

Some important examples are the Nuremberger Code (97), the Declaration of Helsinki (98), the Law of Ethical Approval (SFS 2003:460) (99) and the roles and ethical guidelines as formulated in CODEX (100).

Even if these binding rules are to hand it is the researchers' own ethical responsibility that forms the basis for the research ethics. During the work with this thesis, ethical considerations were made at every step of the process of planning and performing it. The interview guide and the questionnaire were constructed with attention given to ethical values. Great importance was attached to formulating the questions with a dignified tone. The recruitment of informants for the interviews was done in a way that paid respect both to the informed consent of the participants and confidentiality. The informants were approached with information about the study and asked about participating in a way that minimised the risk of putting pressure on them. After permission, the initial contacts were made by telephone. In case of any hesitation about participating the informants were asked to give his or her final answer, either by mail, on the telephone or to any of the members in the home care team. Furthermore, they were repeatedly informed about the possibility of terminating their participation at any time without specifying the reason.

During the interviews I used the same ethical attitude that I use as a social worker in every conversation including sensitive matters about peoples' experiences. During the interviews I tried to be sensitive to the informants' emotions. When they were distressed and cried, I interrupted the interview and waited until they could resume. I allowed time and scope for the informants' emotions and asked if they wanted to break off the interview. However, none of the informant wanted to adjourn the interview. Despite the fact that the conversation could have been trying, several of the informants expressed that it had been valuable to them to have had the opportunity to talk to someone not emotionally involved with the family and without any time pressure. Some of them also declared that the interview had helped them to put their situation into perspective. Furthermore, all the informants were also informed about the opportunity of additional support from the team.

Similar experiences to these were reported by other researchers as well (101-104). Patients and carers in palliative care finds it meaningful to contribute (105) and they are capable to decide whether to participate and negotiating the circumstances in which they wanted this to happen (105).

6 RESULTS

The results of Papers I, III and IV, where hermeneutics has been used for the analysis, are presented both in the form of parts (categories) and as a whole, where the whole represents a synthesis of the categories.

6.1 PAPER I EXPERIENCES OF EXISTENTIAL LONELINESS (PATIENTS AND FAMILY MEMBERS)

The experiences of existential loneliness had impending death as a primary source. The disease had brought about changes both in the everyday life and in the patients' bodies which had aggravated their vulnerability. These changes limited the scope for both patients and family members to ignore life's fragility and reduced their capacity to ward off involuntary thoughts and feelings related to the impending death. When unexpectedly or clearly confronted with threats they were now vulnerable in new and unfamiliar ways. Feelings connected with death were therefore easily aroused. A central feeling was existential loneliness.

Parts

6.1.1 Changes

Changed life conditions and modified experiences of togetherness

Their former existential fundament that had previously been taken for granted had now been changed. The disease had transmuted death from something abstract only affecting others, to something real, concrete and highly relevant. Both patients and family members experienced that they now had insights that others would find impossible to really comprehend.

Some of the external togetherness with others petered out for all those involved. They did not have the strength to socialise with friends or participate in leisure activities in the same way as before. Even the inner sense of togetherness in the family was affected. Routines were changed and family roles were altered. Furthermore, it was no longer possible to share long-term life plans like planning for holidays, and in some cases educational plans, career, grandchildren or a retirement together.

The pathological changes of the patient's body

The patients could experience that their own bodies, which they had relied on earlier, now began to fail and that their former bodily power had been snatched away. Treatments with severe side effects and operations had sometimes damaged the body in such a way that their relationship to their bodies had partly changed from familiarity to unfamiliarity. Being aware that something inside one's own body was growing uncontrollably created feelings of repulsion, powerlessness and estrangement.

As regards their family members, they had experienced both helplessness and powerlessness when they witnessed the patients' sick body falling into decay.

6.1.2 Circumstances

Difficulties in communication

The experiences of existential loneliness were often related to difficulties experienced in communicating thoughts and feelings about the disease and the impending death, both within the family and in relation to others. The difficulties could be due to lack of practice, but also to mutual respect. This was described both by the patients and their family members. This mutual respect was based on empathic feelings but could nevertheless result in feelings of existential loneliness.

Lack of respect

In situations where the patients and family members were not being listened to, they felt hopeless. The patients were exposed to medical contacts where their sick, vulnerable bodies were touched without empathy, sensitivity or attention. In such situations, feelings of isolation and loneliness emerged and the patients felt they were being treated like animals.

Lack of preparedness

To be abruptly informed and being exposed to frightening symptoms and side-effects without being prepared, left the informants unable to adapt emotionally. They felt defenseless and thrown into loneliness.

The patient's suffering

Severe suffering could result in a desire to die, a desire which was difficult for the family members to understand and threatening for them even to hear about. The family members wanted to alleviate the patient's suffering. When this was impossible they experienced feelings of inadequacy, powerlessness and loneliness.

The family member's responsibility

The family members described how they had to shoulder a huge amount of responsibility, due to all the practical details surrounding the situation and the care for the patient. There had been a lot of administrative and bureaucratic struggles and several episodes of prolonged waiting time that had been experienced as very distressing. Since it all was about a loved one's life-threatening disease, an existential dimension was added to the general irritation.

As a whole

6.1.3 The body - A superior category

The interviews bear witness to a growing sensitiveness concerning the fragile body and an awareness of how important a healthy body really is, both in daily life and for one's own identity. It was inside the patient's body that the disease had its base and it was the body that produced signals interpreted as signs of improvement or deterioration. It was the condition of the body that determined whether one could take part or not in everyday life, as well as social interferences and physical and emotional closeness. The family members made their own interpretation of signs and symptoms from the patient's body and depending on what they perceived they related to the situation in different ways. The body came consequently to be an important factor concerning experiences of existential loneliness. Despite the fact that the body is not usually regarded as being an existential aspect, the interview data that emerged stressed that human existence is ultimately based in the body.

6.2 PAPER II EXPERIENCES OF POWERLESSNESS AND HELPLESSNESS. (PATIENTS)

Sixteen percent of the patients stated that they had experienced feelings of powerlessness and helplessness every day or several times per week, 49 % stated that they had done so occasionally and 35 % reported in the quantitative section no experiences of powerlessness. However, in the open-ended responses eight of those 32 who indicated “never powerlessness” in the quantitative part still gave descriptions of situations related to powerlessness and their disseminated cancer.

6.2.1 Triggering Factors (manifest, descriptive focus)

Serious information about the disease

When the cancer was first diagnosed, it affected one’s whole existence and turned the world upside down. The information that the disease was in a late palliative stage gave a realisation about a shortened life expectancy, which resulted in a loss of energy and feelings of both powerlessness and helplessness.

Symptoms

A variety of symptoms and problems that brought about feelings of powerlessness and helplessness were described. The prominent problems mentioned were pain, dyspnoea, nausea, fatigue, urinary and faecal incontinence, sleeplessness, anxiety, cramps and fainting-fits as well as intimate handicaps such as sexual problems in younger patients.

Limitations

The disease and side effects of treatment resulted in psychological and even existential limitations. Bodily functions were affected, as was their spirit. These frustrating restrictions made the informants feel unable to exert control over their own existence, practically and economically and these also constituted trying restrictions on their loved ones.

Dependence

The cancer progression increased dependency on others in everyday life. Receiving the necessary help even in the most private and intimate situations, resulted in feelings of powerlessness. The informants also described feelings of powerlessness in their dependence on the health care systems’ administrative and bureaucratic struggles.

Being ignored

Insensitive behaviour had caused a delayed diagnosis and treatment which triggered feelings of powerlessness. Situations of being ignored or treated as a non-entity were described as triggering as well.

Social loneliness

Involuntary social loneliness contributed to feelings of powerlessness and helplessness. The informants wrote about a diminished circle of acquaintances. People stopped calling and this resulted in feelings of being forgotten.

Uncertainty

Uncertainty was present through all the stages of cancer. Was it cancer or not? Will the treatment work or not? Will there be a relapse or not? And finally, the question about the left in this life. Living with a feeling that anything could happen at anytime and living without any normal time references was experienced as being most frustrating. There was nothing to relate to, act in line with or react to - nothing to brace yourself against.

6.2.2 Aggravating circumstances

During the course of the analysis **suddenness, high intensity and lengthiness** emerged as factors that each in their turn influenced the patients' experiences and the consequences of the triggering factors to a very high degree.

When for example symptoms suddenly appeared, were severe and prolonged or impossible to cure or explain it aggravated the feelings of powerlessness and helplessness. Additional examples were when receiving the bad news about the disease, without being at all prepared and when one had to deal with many different burdens at the same time.

6.2.3 The existential meaning (latent, interpretative focus)

Confrontation with a death threat

The primary cancer diagnosis was perceived as a death sentence. One's own life was threatened and one's life was no longer on the same solid ground that had previously been taken for granted. This profound existential transformation was frightening and difficult to cope with.

Existential loneliness

In situations characterised by a loss of control, altered self-image and threat to life itself, the informants talked about experiences of existential loneliness despite close family bonds. They felt deserted and helpless in a unique way and this provoked feelings that were extremely hard to handle. Seemingly petty everyday situations provoked deep existential insights. This was especially obvious when other people had been talking over their heads, as if they were not there or when they had perceived their own situation was impossible to share or for others to really comprehend.

Hopelessness

The informants perceived themselves as losing charge over their own existence and it was difficult for them to preserve values dear to them and meet responsibilities, both socially and economically. These circumstances had resulted in experiences of losing their human dignity and a threat to their self-image. The informants also described a point of no return.

6.3 PAPER III

INDUCEMENTS FOR TAKING RESPONSIBILITY (FAMILY MEMBERS)

Responsibility was outlined as a demanding task but also as a coping strategy. The informants had increasingly become aware of the patients' multiple physical needs, psychological distress and restrictions in social functioning that the disease had brought about. Furthermore, they had learned that these consequences affected their whole family. In the first place their ambitions had been to ensure that the patient was as comfortable as possible, both physically and emotionally. But their undertakings also included their own well-being and could embrace other family members' as well. By holding on to structures that supported life and meaning they mitigated the impact of harmful reminders of death.

Parts

6.3.1 In accordance with one's outlook on life

The informants' outlook on life was a key factor for assuming responsibility: it was a question of love and attachment, and giving back. It was natural for them to do so and they did it out of their own free will. They were of the opinion that when confronted with life's challenges, one has to jump in and participate to sort things out and to handle the situation. This attitude was referred to as something that had been prevalent in their nuclear family since childhood and seen as a fundamentally human way to react.

Out of love and attachment

Feelings of love, attachment, trust and respect during the relationship had been the foundation for developing ties of affection. The family members were emotionally sensitive, conscious of each other's distress and moved by it. Memories of sharing and closeness, and gratitude over what they had received from the patient in a psychological sense, had resulted in a desire to give something back.

6.3.2 Counteracting reciprocal suffering

Maintaining structures from every-day life as symbols for life

The informants saw to it that every-day chores were maintained as far as possible. The familiar daily routines were experienced as reassuring. It made it possible for all those involved to be surrounded with a comforting framework of reassuring symbols of life.

Maintaining hope

Keeping hope alive was a profound part of their assumed responsibility. It was their duty to counteract signs of resignation that threatened to spread and thereby affecting both the patient and themselves. This was achieved by being encouraging, soothing and physical and by taking the initiative for activities. More often though, keeping hope alive was expressed through an attitude to the whole situation that involved focusing on the present and making the most of the moments given.

Standing up for dignity

The mere thought about the patients' eventual loss of dignity during the impending trajectory towards death evoked the informants' protective instincts. They would not let this happen.

6.3.3 Benefits supporting responsibility

Deepening relationships within the family

The patient's life expectancy had been reduced and there was an urge to care about time, time had become precious. Furthermore, the increased consciousness about the precious values found in togetherness had led to changed patterns when the families came together. This has resulted in deeper relationships within the family.

Growth

The informants had also been forced to face their fears, their own strengths and shortcomings. This had not always been easy but yet it was referred to as developing. They found that the caregiving was not just a matter of giving; it was also about receiving.

6.3.4 Possible consequences of shirked responsibility

Ambivalence, shame and guilt

The inducements for responsibility were not always free from feelings of obligation. Yet, the possible consequences of shirked responsibility were deterrents. It could have exposed the family members to the risk of being tormented by shame and guilt and even loneliness, now or in the future. Shirking responsibility easily provokes such feelings and it is neither a highly esteemed act in society.

As a whole

6.3.5 Not allowing meaninglessness to spread

Feelings of meaninglessness stemmed from the threat of disintegration and unfairness. Unfair and of no use, so many precious things were on the edge of collapse. In that situation it was important to maintain the structures of every-day life, hope and dignity. These structures supported life and meaning, and served to shield off brooding and harmful reminders of death. A shirking of that part of responsibility involved a risk of feelings of meaninglessness spreading and permeating the family's whole existence

6.4 PAPER IV

COPING IN THE PRESENCE OF OWN IMPENDING DEATH (PATIENTS)

All the informants were aware of that their disease was fatal. Even if they kept death at a discreet distance, none of them was even close to denial. Their coping strategies were not aimed at denying death but at making death possible to handle. The informants' cognitive and emotional efforts to do so could be compared with a pendulum swinging between the two extremes of life and death.

Parts

6.4.1 To shield the body and the self

The body was experienced as a source of consolation as well as of alarm. Every indication that the body still worked physically, emotionally or spiritually was a proof of life. As long as the body was free from trying symptoms, it was possible to take part in everyday life and to delight in being alive.

When the disease had damaged the body in such a way that made the seriousness of it all an inevitable fact, it was still possible for the informants to hold on to the parts and functions that were intact. Perceptions of the threat were also diminished by the use of harmless words like “dots”, “bubble”, “nut”, “him” or “it” instead of tumour or cancer and Vitamin C instead of chemotherapy. Diminutive words were also used such as “a bit”, “little”, “small” and “tiny”. The threat could be verbally restricted through different lines of arguments as well. Despite the fact that this reasoning was not realistic and could have an element of magical thinking, it was still helpful.

However, this shield proved weak against resistant symptoms. Pain, fatigue, nausea or difficulties with impaired coordination could easily result in feelings of marked vulnerability and of being exposed to the vagaries of existence. To face these frightening signs with strength, courage, perseverance, a sense of humour and a capacity not to get too engrossed in dark thoughts, was pointed out as important.

6.4.2 Togetherness

Togetherness was an important coping strategy to restrain death and it was experienced on an inter-individual level but also in relation to animals, nature and something greater, a transcendent power, not easy to conceptualise but nevertheless of importance. Valued relationships became even more important and relationships that had been taken for granted earlier, often with partners, children and grandchildren, were now more precious. The informants that had no close family or friends extended their frames of reference and involved distant relatives and even staff in their close circle of acquaintances.

The prospect of perhaps meeting already deceased family members and friends, after death, was another aspect of valued togetherness.

6.4.3 Involvement

The disease had brought about both a feeling of separations and a more restricted life. That had resulted in feelings of isolation and despondency. These experiences could be counterbalanced by moments that indicated involvement. To still be able to join in, be counted upon, served a purpose and share feelings with others were described as important experiences. Also the maintenance of commitments and skills, even if to a limited extent, could serve as a useful source for coping.

6.4.4 Hope

Rays of hope had sustained the patients through trying periods of distressing symptoms, anxiety and powerlessness. Their hope had been linked to so much more than the hope of being cured. In the interviews they talked about their desire to live without distressing symptoms, their desires to be able to stay at home or at least be spared from feelings of loneliness.

6.4.5 Continuation

The informants valued being a part of a life-twist that had its roots in the past and continuing into the distant future. They were, much more than before, observant of the present as a result of a heritage going back generations. To be a part of that twist with all its strands that would continue to exist for all times, gave some reassurance of immortality. Children and grandchildren were central to this. Important creations, skills taught, shared experiences and providing something that would be of use for others are additional examples of lasting strands in the life-twist.

Thoughts about annihilation were frightening. Therefore it was comforting to try to hold on to the possibility of a something, even if it was nothing tangible.

As a whole

6.4.6 Balancing death with manifestations of life - a tentative process

The interviews were conducted on one occasion, but they were stories about a process. The informants described both past experiences and their thoughts about the future. The process was hard to encapsulate in any form of consecutive stages along a time axis. It was characterised by tentativeness and erratic results, and conveys a picture that included victories as well as failures. The patients strived to contain hurtful feelings originating from their impending death within endurable limits. It was of the outmost importance for them that hurtful feelings connected with death did not multiply and consumes their whole existence.

Aspects that were pointed out as important for successful coping were personal factors, support from others, a basic assumption about oneself and the world that could adjust and embrace death in a way that implies values of vital importance. Not only facts with firm links to the here-and-now-reality contributed to the process of developing useful strategies. Memories, daydreams and fantasies were of importance as well.

7 DISCUSSION

The overall aim of this thesis was to obtain knowledge about the existential crisis caused by an incurable cancer disease and how patients and family members manage the crisis.

Two important factors had affected the informant's daily life to a considerable degree, namely experiences of existential loneliness and the impact of the patient's disease-racked body. Other factors of great importance were experiences of helplessness and powerlessness and the coping with challenges and threats.

7.1 EXISTENTIAL LONELINESS

Experiences of existential loneliness were a frequent theme in all the studies. They are thoroughly described in study I, presented as a part of powerlessness in study II, a threat necessary to cope with in study IV and as an inducement for family members responsibility in study III. From my point of view this was initially an unexpected finding. On second thoughts it should presumably not have been so. When Yalom writes about different forms of loneliness he stresses the lack of absolute borders between them. On the contrary the borders are semi permeable. That means that they can both interact and masquerade. In the presence of impending death it is plausible that experiences of interpersonal (social), intrapersonal or existential loneliness could be transformed into a common experience of existential isolation which is the type of loneliness that is intimately intertwined with death (106). In fact death is designated as the event that more than anything else symbolizes man's profound loneliness and the inevitable separation and isolation from others (106, 107) and the one event when existential loneliness is most manifest (108). Several authors have also stated that the experiences of loneliness are closely related to death and are one of the core factors that make dying distressing (109-113). Anything else can be shared, but one's own death cannot.

Considering this, why is loneliness not a factor that has a salient position in the active total care that is the essence of palliative care? There may be several reasons. Communicating loneliness could be difficult and something people hesitate to discuss because, at least in western societies, loneliness is a sign of failure (114) and therefore suggests shame. The low status of loneliness could contribute to making it a subject that is neither mentioned nor asked about. The threatening dimension of existential loneliness (3, 106-108) could also contribute to its neglected position. The encounter with another person's existential loneliness can evoke feelings hard to handle for all involved, including also staff within palliative care. It is hard to meet existential pain, most of all when it is an anguish for which we can do nothing. Existential loneliness is a human basic given and therefore impossible to eliminate (3, 115) although social contacts and connectedness can make it possible to endure (3). The encounter with the experiences therefore easily evokes powerlessness and feelings of failure within palliative care staff. This can of course appear within family members as well. Furthermore, they can misunderstand the patient's existential loneliness and interpret it as social loneliness (3) being a result of deficient attention from them.

7.2 THE BODY

The impact of the physical body was striking and evident in all four studies as well. Despite the fact that the body is not usually regarded as being an existential aspect, the

results of this thesis stress that human existence is ultimately based in the body. Both patients and family members that took part in this study had experiences that the patient's body had become a detector of life and death during the time with the disease. As long as the sick body was free from distressing symptoms it was possible for all involved to keep death on a discreet distance and join in every day life. However, when bodily problems occurred they promptly became a warning devise about the seriousness of the situation.

Similar experiences have also recently been shown in Olav Lindqvist's thesis about men with prostate cancer (116). His informants described a cyclic movement between experienced wellness and illness depending on the control of bodily symptoms (117). Understanding and, to some extent, being in control of bodily problems helped them disregard the fact that they had an incurable cancer and instead reclaim wellness. That physical effects of cancer are central in the quest for well-being is shown in other studies as well (118, 119). These findings speak to the importance of adequate treatment for bodily symptoms since it is a vital component of the patient's coping.

All these results combined elucidate the central role of the body in a palliative context. The body's significance for the human identity is previously described by Freud (120) who stressed that the ego primarily is a "bodily ego" and by Merleau-Ponty (121) who said that human beings both have and *are* a body. The Swedish psychiatrist Johan Cullberg call our body "the earliest and most profound personality foundation" (38) p. 95. These statements underline that the human subject, as well as her consciousness, are bodily based, and that people therefore relate to themselves and others primarily through their bodies. As a result of this, changes in the body during a cancer trajectory, have influences on a person's whole identity and on how she experiences and relates (122, 123). That change in the body can give rise to experiences of unfamiliarity and homelessness is described earlier (124-126) and is now elucidated in this study as well.

7.3 HELPLESSNESS AND POWERLESSNESS

The informants were often successful in finding strategies that helped them to preserve meaningful values and parry threats to these values. However, there were circumstances that weakened or destroyed the informant's coping ability. This became apparent in Study II where the patient's experiences of helplessness and powerlessness were investigated. Etymologically the original meaning of the word helplessness is an inability to help oneself, whilst the meaning of powerlessness is related to an inability to defend oneself. It is important to high-light the result in this study which shows that in a palliative context both helplessness and powerlessness have a deep existential meaning since what which one is powerless against is a death-threat. It became evident under certain circumstances. Challenges caused by symptoms, loss of control and autonomy, of being ignored, lonely and uncertain constituted the basis for the experiences of helplessness and powerlessness on a manifest level. Those feelings were reinforced by the aspects of suddenness, high intensity and lengthiness, factors that we name as aggravating circumstances. These circumstances influenced the situation in ways that made it overwhelming and therefore difficult to manage. They undermined the patient's coping skills and it became difficult for them to keep on parrying off threats and keep death at a discreet distance.

Richard Lazarus' and Susan Folkman's writings about challenges and threats (27) p.32 can contribute to an understanding of the impact of aggravating circumstances that is of great clinical value. According to them it is important to distinguish between them in

the appraisal process. They underline that they are related and can occur simultaneously but despite this, they must be considered separate constructs. Both call for the mobilization of coping efforts but give rise to different emotions and therefore they hold different cognitive judgements. A threat concerns harm or loss and is characterized by negative emotions such as fear, anxiety and anger. A challenge focuses on the potential for gains and growth in the encounter and arouses mainly pleasurable emotions such as eagerness and excitement. A challenge, which is possible to cope with can therefore, despite severe circumstances, promote and maintain well-being (127). Concerning this it is possible to regard aggravating circumstances as aspects that transform the patients' experiences of helplessness and powerlessness in such a way as they were appraised as threats, hard to cope with instead of challenges, not so hard to cope with.

If using Cassel's writings about suffering (128, 129) the aggravating circumstances could be considered as factors that intensified the patient's distress to an extent where that person's intactness was intimidated. According to Cassel suffering is experienced by persons, not merely by bodies, and has its roots in challenges that are perceived as overwhelming and therefore threaten the intactness of the person as a complex psychosocial and existential entity. It can arise in relation to all aspects of a person: social roles, group identification, the relationship with self, body, family or the relationship with a transpersonal, transcendent source of meaning and hope.

It seems important to reduce the impact of aggravating circumstances within palliative care, in order to facilitate the dying patient's ability to cope. The fact that suddenness could be distressing in connection with information about a serious disease has been pointed out earlier (130-132). On the whole suddenness in association with serious diseases is a factor that should be considered aggravating. It prevents people from organising new information in a way that makes it comprehensible for them, and is also an obstacle to the psychosocial transition, a process necessary for the integration of bodily and existential changes (133). Therefore literature on how to break bad news recommends "giving warning shots" (134, 135).

7.4 RESPONSIBILITY

In the interviews with the family members responsibility was outlined as a demanding task but also as a coping strategy (Study III). Despite feelings of ambivalence and sometimes overwhelming demands they had taken on the responsibility. Death is threatening. It devastates life and values, it is lonely and it is unknown. Cassel's theory about suffering (128, 129) is relevant to gain an understanding also about the family members' experiences since the intactness of the everyday life, the family and the future were threatened. This urged them to hold on to significant values such as togetherness, involvement, hope and continuity. Factors that were interpreted as threats to these values like resignation and meaninglessness were warded off. They did this by taking care of the retaining capacities remaining within the patient's body and mind, by holding on to the daily routines, and by maintaining hope and dignity. During the course of care they took advantage of their capacity to create opportunities for positive events and by infusing ordinary occurrences with positive meaning (71, 72, 136). Preserving meaningful values was essential (137) in the family members' inducements for taking on responsibility

7.5 COPING WITH DEATH

The patient's shaping of coping strategies (Study IV) were formed during a cognitively and emotionally oscillating movement between extremes of life and death. It is noteworthy that any manifestation of life in this counterbalancing process was of such profound significance. Connections to life and to a symbolic future e.g. memories that will remain when they have died, helped the patients to adjust to the idea of ceasing to live and to ending their existence at their own pace. Ideas about which aspects characterize life and death respectively are to a great extent common (111, 138). Togetherness, involvement, hope and continuation are aspects that most people probably consider manifestations of life while isolation, exclusion, resignation and annihilation are connected with death. The patients were highly perseverant in their endeavours and used every means available when they created their coping strategies, which indicates their importance.

Togetherness, the opposite pole to loneliness (Study I) stood out as a life-link that well served its purpose in the informants' coping (Study IV). The most valued was described primarily in relation to significant people, but not only. A feeling of connectedness with animals and nature was described as significant as well. So was a perceived togetherness with a transcendent power and the prospect of togetherness beyond death. It is worth noticing that building block in dying people's coping strategies can imply links to a transcendent power or to a possible continuation of life after death even when a person considers herself as non-religious. The fact that a connection to life and to a symbolic future can counteract the consequences of terminal illness is described earlier in a palliative context (139) and also in the field of occupational therapy (140) as well as in the concept of generativity (141).

There is a crucial difference between coping with a disseminated disease and the focus is on living as long as possible and coping with one's impending death in a situation when one realises that life will soon come to an end. A continuing life will be embraced within a well-known frame of references. Despite differences caused by the disease, the continuing life will proceed in a familiar world. Coping with death and ceasing to be imply coping with something that is totally un-known. There is no existing frame of reference that is valid for death. For the patients to be able to make usable coping strategies faced with their own one impending demise they had to transform death into something possible to conceptualize, to brace themselves against. The patients used references from life when they shaped strategies for coping with death. Their aim was to shield themselves and others from harmful feelings, but also to transform a possible nothing into a something. These findings are in accordance with the understanding of death anxiety that is presented in existential philosophy. In that context it has been described as a reaction to the constant threat from an ontological non-being (6, 35) or from nothingness (46).

The circular or balancing way of human conceptualization that is elucidated in this thesis is described in several other studies as well (111, 137-139, 142-144). Hermeneutics can be used as a theoretical frame to explain this frequently occurred phenomenon. According to hermeneutics this is the way humans react in unfamiliar situations that they need to grasp. When they do not understand, they interpret and the process of interpretation is circular (35) and it moves between the well-known and the un-known. The informant's strivings to conceptualize their situation start in the well-known life and continue on in the un-known death. The tacking procedure goes on between what is not understood and then back to sources that can contribute to a deeper understanding of their situation.

7.6 METHODOLOGICAL CONSIDERATIONS

Hermeneutics was chosen in Study I, III and IV, since the interviews concerned questions about dying and death, topics where there are good reasons to assume that the informants would not give explicit expressions due to their fears or defence mechanisms (2, 3, 6). Therefore it was considered important to choose a method for analysis that allows interpretation.

Both the choice of using existential psychology especially as presented by Irving Yalom (3) and the theory of meaning-based coping (29, 71) was decided with the intention of gaining understanding of the existential crisis. Both these frames are results of earlier extensive research about how people struggle with existential challenges and therefore have considerable knowledge to offer. When using predefined frames, the risk of missing important aspects that are outside the framework must be considered. Still, the advantages outweigh the disadvantages. Besides the contribution of previously gained knowledge, it gives the opportunity to concentrate the analysis and gain a deepened understanding. Yalom's concept of existential challenges that severely ill people have to confront and handle, has also been used as a theoretical frame in doctoral theses studying the existential crises in brain tumour patients and their families (37) and in studies of family members of dementia patients (145).

Viktor Frankl's logotherapy provides important knowledge about sources where people's meaning can stem from. His view on responsibility as the fundament for meaning has proven valuable in Study III where it contributed to a deepened understanding of the family member's inducements for taking responsibility. However, in our experience logotherapy was not useful in gaining a corresponding understanding of existential loneliness and powerlessness.

In Study I, III and IV we aimed at a maximum variation sampling, in order to cover as many aspects of the phenomenon as possible. The data should therefore be transferable in palliative care settings in secularized western societies similar to Sweden. In a qualitative study the results are always context-bound and therefore not possible to generalise, but can be transferred to other similar contexts.

Even if the informants included in the study were more or less successful in their efforts to cope none of the informants in this study were caught up in brooding. It is highly doubtful if it is possible to find such patients for this type of studies. Besides their emotional well-being, another hindrance is the fact that it is easier to relate one's successful attempts than one's failures. These circumstances also raise the question about in what situation informants are when participating in depth studies. There are reasons to believe that it is when they feel strong and are having good days.

8 WHAT THIS THESIS ADDS

The result from this study will contribute to an understanding and heightened awareness of the complex process going on within patients and family members in palliative care. The emotional and cognitive processes, struggles, successes and failures, that the informants revealed, are experiences shared by many, even if what is noticeable externally is only a pale reflection of what is going on internally.

The elucidated impact of aggravating circumstances on the patients' coping is clinically valuable. When patients are emotionally overwhelmed the situation is perceived as threatening and therefore difficult to cope with. In order to support patients' coping such circumstances should therefore be avoided as much as possible.

The complex situation revealed in family members' inducements for taking responsibility hopefully contributes to an understanding of the conflicting desires, feelings and needs of the family members in palliative care. Through including such issues of the care-giver role in the dialogue with family members, staff could lighten the care-giver's burden and even enhance their existential awareness and growth.

It is worth noticing that building blocks in dying peoples' coping strategies can imply links to a transcendent power or to a possible continuation of life after death even when a person considers herself as non-religious. It is not only facts with firm links to the here-and-now-reality that contribute to the process of developing useful strategies. Memories, daydreams and fantasies are of importance as well.

The circular or balancing way of human conceptualization is a highly individual process and can therefore not be manoeuvred by others. Still, it can be supported by staff offering the opportunity to talk, pose questions and investigate alternative standpoints and solutions to the actual situation at hand. Such support should be offered, but a person declining to participate in such an endeavour has to be respected.

The results of this thesis illuminate the profound and inevitable impact of death-threat in a palliative context. Primarily it exerts influence on the patient but it affects family members as well. Existential concerns that are closely related to death such as loneliness, guilt and meaninglessness are impossible to eliminate. They are basic givens for everyone. However, as staff we can offer togetherness and support in a way that may alleviate distress.

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11 APPENDICES

11.1 APPENDIX 1

INTERVIEW GUIDE, STUDY I, III AND IV

- Age/Marital status/Occupation
- Can you tell me something about your disease? How long have you been ill?
- How do you think the disease has affected you?
- Is there anything that seems more important now, compared with when you were healthy?
- Can you tell me if there is anything that can make you feel happy/strong/hopeful?
- From where do you get courage?
- Where do you seek consolation?
- Can you tell me about something that takes your courage away from you/ that makes you weak/frightened?
- Do you define yourself as religious?
- Do you believe in *anything*?
- Where do you find peace?
- Do you think that life continues after death?
- Do you believe that existence consists of something more than what we know for sure?
- Can you tell me about something that really matters to you?
- Have you got a name for those matters we have been talking about during this interview?
- Is there anything that you consider important that I haven't asked?

Below follow some questions concerning your possible experiences of meaning and also powerlessness or helplessness, connected with the disease and need for support. Write as much as you desire, lengthy or short, all answers are valuable.

If you do not wish to describe your experiences we would be grateful if you anyway could mark on the last side if you have had experiences of meaning respectively powerlessness or helplessness during the time of the disease (question 8-9). If the space for writing is too limited, please use another paper or write in the back.

1. What is meaningful to you?

2. Would you describe an occurrence during the time that you have been sick that was meaningful and important to you? You can describe more than one situation if you like to. We have a special interest in the time when you have been enrolled in the APHC-team.

3. Do you think that the health care system can/could have facilitated feelings of meaning?

4. What is powerlessness or helplessness to you?

5. Would you describe an occurrence during the time of the disease that resulted in feelings of powerlessness or helplessness? How do you tried to cope with/solve the situation? Did it help? You can describe more than one situation if you like to. We have a special interest in the time when you have been enrolled in the APHC-team.

6. Do you think that the health care system could have done anything to prevent or facilitate your feelings of powerlessness or helplessness? If yes, in what way? If no, why not?

7. You, who rarely or never have felt powerlessness or helplessness, what do you think have helped you to avoid it?

8. During the time in the APHC-team I have experienced meaning (about)

- Every day
- Several times per week
- Every month
- Occasionally
- Never

9. During the time in the APHC-team I have experienced powerlessness or helplessness (about)

- Every day
- Several times per week
- Every month
- Occasionally
- Never

Do you want to add anything else?

Thank you for your participation!