Dissertation for the Degree Philosophiae Doctor (PhD) in psychology of religion
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The illness experiences of older people with incurable cancer in specialized palliative healthcare contexts
A qualitative study in clinical psychology of religion of the interactions between daily living and existential meaning-making
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Paper I

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Acknowledgments

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Summary

Older people living with incurable cancer as a chronic disease represent an increasing proportion of the patients receiving palliative care in specialized healthcare contexts in Norway. This population’s multidimensional healthcare needs, including cultural and existential dimensions, present an identified challenge for public health, and public mental health in the near future. However, little is known about how they experience living with the disease and about the psychological functions of existential meaning-making experiences in their daily living. Research in both palliative care and clinical psychology of religion in Scandinavian contexts has been quite limited. Hence, this qualitative study was seen as a contribution to addressing these gaps.

Twenty-one older people with incurable cancer, 12 men and nine women aged 70-88, were interviewed with a semi-structured guide. The interviews were transcribed verbatim and analyzed with both inductive and deductive strategies, in a progressive manner. The study was placed within the hermeneutical tradition in psychology due to the focus on interpreting and understanding meaning phenomena in text material. The research question was: How do older people experience living with incurable cancer in daily living - with special reference to the psychological functions of existential meaning-making experiences? Hence, the aim was both to describe how the participants experienced daily living, and to explore and understand the psychological functions of their existential meaning-making experiences. The overall research question was operationalized in this study as the following three sub-questions, each forming the focus of one of the three papers: I How do older people with incurable cancer experience daily living?, II How do older people with incurable cancer experience the existential meaning-making function in daily living from a life-span perspective?, and III How can cultural and existential meaning-making analyses contribute to an understanding of the reframing process in an ethnic Norwegian majority population of older people with cancer?

The concept existential meaning-making was used as the main concept. The understanding was broad, including related concepts such as spirituality/spiritual, religion/religious, worldview, and meaning. The choice was based on research in clinical psychology of religion in Scandinavia (DeMarinis, 2008; DeMarinis, Ulland, & Karlsen, 2011; Ulland & DeMarinis, 2014). Here the need for applying concepts that are suitable for a broad spectrum of meaning-related expressions, including a culture-focused perspective for all patients has been emphasized. The overall approach to existential meaning-making was therefore functional. This implied exploration of how the study’s sample experienced the roles and purposes of
existential meaning-making for dealing with the adaptation process as incurably sick with cancer.

A multilevel interdisciplinary theoretical perspective, emerging from psychology of religion (Emmons & Paloutzian, 2010) was used in order to encompass the theoretical areas needed to capture the complexity and diversity in the experiences of older people with incurable cancer. Other disciplines were added to the main discipline of clinical psychology of religion to throw light on certain issues and aspects. In addition, the perspective allowed for multilevel analysis of the existential meaning-making experiences in the sense that valid interpretations could be given from different perspectives.

In Paper I, the phenomenological descriptive method called “systematic text-condensation” (Malterud, 2012) was applied as analytic strategy for the interview text material. In Paper II, theory-driven analysis was applied as a strategy for analyzing the same material. Here, an operationalized existential meaning-making framework was added to the model ‘selective optimization with compensation’ (abbreviated to SOC) from life-span developmental psychology (P. B. Baltes, Lindenberger, & Staudinger, 2006). In Paper III a theory-driven analysis was employed as well. Four cases, representing the range of meaning-making expressions from the total group of 21 older people, were analyzed with cultural- and existential meaning-making analyses grounded in medical anthropology (Kleinman, 1980). Though the analyses were done separately, there is a progression represented in that the findings from Paper I provided a base for the analyses in Papers II and III.

The objective in Paper I was to describe how this group of older people with incurable cancer experienced, from a subjective perspective, their daily living while receiving specialized palliative healthcare. The analysis showed that they expressed strong links to life in the present in terms of four subthemes: to acknowledge the need for close relationships, to maintain activities of a normal daily life, to provide space for existential meaning-making, and to name and handle decline and loss. In addition, the study’s sample experienced that specialized healthcare contexts strengthened the link to life by prioritizing and providing person-centered palliative care. On an overall level existential meaning-making and resilience were identified as the main- and interrelated processes for these older people.

The objective in Paper II was to understand how the group of older people with incurable cancer experienced the existential meaning-making function in daily living from a life-span perspective. The findings from Paper I concerning the processes of existential meaning-making and resilience were taken a step further here. The SOC model was applied in a
deductive analysis of the same interview data. Based on the analysis in Paper I the existential meaning-making experiences were operationalized as four concerns; a belief frame, value in and meaning in life, life attitude, and relation to future and death. This was added to the SOC model of selection, optimization and compensation. The results showed that the study’s sample experienced the existential meaning-making function on two levels. On an overall interpretive level it was an important component for reaching and continuing with most important goals in daily living. The existential framework permitted a more comprehensive understanding of resilience, allowing for both restoration and growth dimensions to be identified. The second level was the daily living strategy level. Existential meaning-making was involved in a complex interaction with behavioral resources and resilience for continuation of life goals and more realistic goal-adjustments. A few experienced existential meaning-making dysfunction.

The objective in Paper III was to understand how the group of older people with incurable cancer reframed their illness experiences in light of existential meaning-making adjustments. The need for this focus emerged from the analyses in Papers I and II, finding that the patterns and content of these experiences were very different, pointing to different cultural processes with different orientations of importance for clinical reality. The four case illustrations represented the range of meaning-making expressions from the total group of 21 older people: atheistic/humanistic, religious, and spiritual. The main finding was that the cases reflected heterogeneous cultural processes while living with incurable cancer. Independent of the cultural variation, the reframing appeared to contribute positively to constructions of illness and health, to relating to the surroundings, and to the adjustments made in daily living. The results also appeared to show that illness reframing, linked to the existential dimension, led to changes in the other dimensions in the applied cultural framework.

Main results and implications: In this qualitative study of a group of older people with incurable cancer, they reported experiencing a strong link to life in the present. Existential meaning-making and resilience represented the overarching and interrelated processes for understanding the adaptation process in daily living. Cultural- and existential meaning-making analyses contributed to a more nuanced understanding of the participants’ varied interpretations and modifications of living with incurable cancer. The results point to the need for including these types of analyses and their resulting information in the clinical process for better understanding a patient’s framework of interpretation. To combine the SOC model and the existential meaning-making framework with the resulting more comprehensive approach
to resilience, might provide a fruitful next step in both the theoretical and the clinical development for palliative care populations. Healthcare professionals can make use of this information in treatment planning and for the identification of psychosocial, cultural, and existential meaning-making resources to support older people and to strengthen the person’s own life resources.
1 Introduction

Age is a strong determinant for cancer risk. In Norway in 2013 there were 30,401 new reported cancer cases (Cancer Registry of Norway, 2015), and 50 percent of these were people aged 70 and older. In specialized healthcare cancer was the second most frequent cause of hospitalization between age 70-79 (Mundal & Thonstad, 2013). Factors such as the aging population, and advances in earlier detection and in medical treatment and supportive care have led to the current reality that a growing number of people are either recovering fully or living with an incurable cancer disease as a chronic disease (Payne, 2007; Rowland et al., 2013). As a result ‘survivorship research’ has emerged after 2000. According to the latest annual report from the Cancer Registry of Norway (2015, p. 71) the growing number of patients with incurable cancer disease “represents an increasing demand for personnel and costs in the health care system”. Seen from the patient’s perspective in a Norwegian study of patients 70 years and older, there is a need for long-term palliative care in specialized healthcare contexts (Grov, Dahl, Moum, & Fosså, 2005).

Despite this situation both palliative care research (Goldstein & Morrison, 2005; Hammond, Teucher, Duggleby, & Roanne, 2012; Hughes, Closs, & Clark, 2009) and ‘survivorship research’ (Rowland et al., 2013) have predominantly focused on younger age groups. In 2007 the European Association for Palliative Care (EAPC), which is the international organization in the field, established the taskforce “Palliative care for older people” (2014 b) for increasing the attention on this group of patients. It concluded its work with the World Health Organization (WHO) publication on better practices in 2011 (S. Hall, Petkova, Tsouros, Costantini, & Higginson, 2011), emphasizing that cancer in older people has become a health priority for the WHO and that research on this group is seen as paramount. Correspondingly, little attention has been paid specifically to this group in clinical psychology of religion (Torbjørnsen, 2011) and related sub-disciplines such as sociology of religion (Ahmadi, 2006), studies on religion and health measures (Sørensen et al., 2012), and health science (Moestrup, 2015) in Scandinavian contexts. These studies have mainly included patients aged 20 and older. Therefore, the main reason for selecting this age group seemed obvious in terms of addressing an under-researched yet specially-identified group of patients.

This overview text is structured into six chapters. Chapter 1 includes presentation of the empirical material, research questions, main concepts and theoretical frame of reference. In
Chapter 2 the theoretical framework and the research review are presented. Chapter 3 contains the research design and methods. The results are presented in Chapter 4, and the discussion of the results and the methods in Chapter 5. Chapter 6 contains reflections on contributions, implications, and future research.

1.1 Population and empirical material
In this study 21 older people with incurable cancer, 12 men and nine women aged 70-88, were interviewed with a semi-structured guide while receiving palliative care in specialized healthcare contexts in the southeastern part of Norway. This specific group of older people is designated as ‘participants’ or ‘the study’s sample’ in this text. The empirical material consisted of the transcribed interview material, comprising a text of 370 text pages. The study, which was focused on understanding and interpreting the meaning of lived experiences, was placed within the hermeneutical tradition in psychology (Belzen & Hood, 2010).

1.2 The central research question, aim, sub-questions and the study’s phenomena
The study’s central research question was: How do older people experience living with incurable cancer – with special reference to the psychological functions of their existential meaning-making experiences? Terms such as ‘patient’ or ‘palliative care patient’ were excluded in favor of ‘older people’ in order to call attention to the subjective and daily character of their experiences, that is the phenomenological aspects. All participants in the study had been diagnosed with the disease, incurable cancer, through specialized healthcare. Regarding the second part of the research question, the term psychological function involved an exploration of the role or purpose the existential meaning-making experiences served for the participants in their daily living. The functional understanding was derived from clinical psychology of religion, see sections 1.4 and 2.2.

The research question actually contained two interrelated questions, one general and one specific, the latter being the dominant one. Thus, the aim was both to describe how older people with incurable cancer experience daily living, and to explore and understand the psychological functions of their existential meaning-making experiences. Accordingly, the phenomena being studied were: 1. older people’s ways of making meaning of their cancer
illness experiences, and 2. the psychological functions of their existential meaning-making experiences.

The central research question was operationalized into the following sub-questions, addressed through the study’s three papers:

Sub-question 1, Paper I: How do older people with incurable cancer experience daily living?
Sub-question 2, Paper II: How do older people with incurable cancer experience the existential meaning-making function in daily living from a life-span perspective?
Sub-question 3, Paper III: How can cultural- and existential meaning-making analyses contribute to an understanding of the reframing process in an ethnic Norwegian majority population of older people with cancer?

1.3 Conceptual clarifications
In this section the four main concepts in the study are presented. These are: illness experience, palliative care, existential meaning-making, and reframing.

1.3.1 Illness experience
The conceptual understanding of illness experience was derived from the prominent medical anthropologist Kleinman (1980, 1992, 2013; 1991), making a distinction between disease and illness and including an ethnographic understanding of experience. This concept was explored in Paper III. Disease refers to the medical system with diagnostic classifications and specific treatment interventions. Disease, per se, was not in focus. Instead, focus was on the illness experience represented by older people’s responses to their incurable cancer disease. This included physical reactions, psychosocial experiences, and meaning(s) ascribed to the illness. The latter was framed as existential meaning-making (sub-section 1.3.3). The term experience was understood as a holistic, individual, relational, continuous, and contextually-anchored process. Holistic refers to the dimensions in the WHO definition of palliative care (2014 a): physical, psychosocial, and spiritual (sub-section 1.3.2). The other terms were derived from an ethnographic understanding of experiences (Kleinman, 1992), emphasizing the flowing and open character of experience, and how this facilitates connections between the individual and other persons. This takes place within the local worlds of each person, also framed as micro worlds. When illness and experience were combined in the present study, it allowed for
exploring psychosocial processes and patterns in existential meaning-making within the micro worlds of older people with incurable cancer.

1.3.2 Palliative care
The term ‘palliative care’ used here encompassed three different usages. The first use was that of palliative care as a medical discipline, specifically related to the clinical context of palliative care in specialized healthcare units, situated in two local hospitals in southeastern Norway. Palliative care is included in the public healthcare system and divided into three care levels, (Haugen, Jordhøy, Engstrand, Hessling, & Garåsen, 2006; Norwegian Directorate of Health, 2013).

The second use concerned the recruitment sites’ understanding of ‘palliative care’ in terms of a clinical approach to patients. A broad understanding was identified, which is in line with the latest WHO-publication on palliative care for older people (S. Hall et al., 2011) and the Norwegian guidelines for palliative care (Norwegian Directorate of Health, 2013). This implies that palliative care starts at a low base at the time of diagnosis and rises with disease progression and the end of life. The broad understanding of a clinical approach builds on the WHO definition of palliative care (2014 a), which is presented below.

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (World Health Organization, 2014 a).

The third use of the term ‘palliative care’ concerned the research field of palliative care. The three levels of the term are further presented in section 2.1.

1.3.3 Existential meaning-making
The relevance of research in this domain was strengthened by the fact that spiritual care is integrated into the WHO-definition of palliative care. However, despite the fact that spiritual care is a distinctive research field in palliative care (Cobb, Dowrick, & Lloyd-Williams, 2012; Vivat, 2012), it is only at a developmental stage (Selman et al., 2014) and therefore was not selected as the basis for the conceptual understanding of this type of information in the current study. Rather, the concept existential meaning-making was chosen for pragmatic and culture-tested reasons as it was considered as appropriate for assessing this type of information from
this particular group of participants in the clinical context of specialized palliative healthcare in Norway. The choice was based on research in clinical psychology of religion in Scandinavia (DeMarinis, 2008; DeMarinis et al., 2011; Ulland & DeMarinis, 2014). Here the importance of selecting a concept that can include a broad range of existential meaning expressions, identifying a type of information category applicable for all patients, has been addressed. Thus, this concept was used as the main concept in the present study, allowing for the inclusion of related concepts and typologies such as spirituality/spiritual, religion/religious, world-view, and meaning.

A definition developed for Scandinavian contexts by DeMarinis was applied as seen below. Extracts from the definition were used in both Paper I and II. In Paper III it was further elaborated upon by the existential dimension in the medical-anthropology culture model. The concept is further presented in sub-section 2.2.1.

The existential dimension is focused on the individual’s understanding of existentially and the way meaning is created. The dimension includes worldview conception, life approach, decision-making structure, way of relating, and way of understanding. It also includes the activities or expressions of symbolic significance, such as rituals and other ways of meaning making. As each individual has an existential dimension and spiritual nature, the varieties of their expression include many different kinds of meaning systems. These can be associated with traditional religious systems or with other meaning-making systems. For the individual it is also possible to have elements of different systems combined (DeMarinis, 2008, p. 60).

1.3.4 Reframing

Placed within the hermeneutical paradigm in psychology the main point of departure was to view the human world as a continuous and contextually-anchored process of constructing and reconstructing meaning. The meaning construction process is connected to human activities such as thinking, feeling, and talking (Belzen & Hood, 2010). This process was restricted to the psychological and cognitively-based term reframing. The understanding of the concept was derived from the psychotherapeutic tradition (Mattila, 2001). In a widely used definition by Watzlawick and colleagues from 1974, considered as classical, reframing is understood as:

to change the concepts and/or emotional settings or viewpoints in relation to which a situation is experienced and place it in another frame which fits the ‘facts’ of the same
concrete situation equally well or even better and thereby change its entire meaning (Mattila, 2001, p. 7).

The aim with reframing in clinical contexts is to help patients in relabeling the meaning or implications attributed to behavior. This may in turn facilitate positive effects on attitudes, responses, and relationships (Mattila, 2001). The concept is further presented in section 2.2.

1.4 Clinical psychology of religion

Theory wise, the study was anchored in psychology of religion, and its subarea of clinical psychology of religion. Psychology of religion is a subfield of psychology (Emmons & Paloutzian, 2010). The subarea of clinical psychology of religion focuses on the relation between existential meaning-making and mental health in clinical contexts (Van Uden & Pieper, 2003). Insights from general psychology of religion are applied to the field. Clinical psychology of religion guided the direction of the study in three ways. First, it constituted a theoretical basis for exploring both functional and dysfunctional aspects of existential meaning-making experiences in a clinical population. Second, it allowed for the application of the model ‘selective optimization with compensation’ (SOC) from life span developmental psychology in Paper II. Third, it allowed for linking the study to the growing amount of research in clinical psychology of religion in Scandinavia. Central researchers in this field have emphasized the necessity of hermeneutical- and contextual perspectives in research (DeMarinis & Wikström, 1996). In this way, underlying values and normative frameworks that affect the research can be identified. Both as the particular clinical context and as a growing research field palliative care dominated the hermeneutical- and contextual perspectives in the study.

In psychology of religion the “multilevel interdisciplinary paradigm” (Emmons & Paloutzian, 2010, p. 243) has been recommended for research in order to guide the field. In the current study, this paradigm was selected as the theoretical framework for the exploration and understanding of the participants’ illness experience, with clinical psychology of religion as the central theoretical base.
2 Theoretical framework: building from a multilevel interdisciplinary paradigm

As noted in the introduction the “multilevel interdisciplinary paradigm” (Emmons & Paloutzian, 2010, p. 243) from psychology of religion was selected as the theoretical framework. The paradigm recognizes “the value of data at multiple levels of analysis while making nonreductive assumptions concerning the value of spiritual and religious phenomena” (p. 244). This means that a single disciplinary approach is seen as incapable of capturing the comprehensive aspects in the domain of existential meaning-making. Perspectives from related disciplines are added as supplements to the main discipline in order to elucidate certain aspects or add additional information. Non-reductive assumptions are in focus concerning the value of existential phenomena. This means acknowledging that valid explanations for the same phenomena can be made with multilevel data analysis from within psychology itself and from outside by crossing the disciplinary boundaries.

The background for introducing the paradigm is related to the progress in psychology of religion during the past 25 years. Due to rapid growth in research, there has been a movement away from the measurement paradigm towards an emerging interdisciplinary paradigm. When considering textbooks, handbooks, systematic reviews, and new research areas in the field, the authors conclude that the field has gone beyond focusing primarily on measurement. The paradigm shift addresses the expansion of research on topics within almost every area of psychology, leading to developments both internationally and cross-culturally. Also, interdisciplinary collaboration with researchers in disciplines such as anthropology, philosophy, neuroscience, and cognitive science has contributed to the shift. An interdisciplinary approach to existential meaning-making means that psychology of religion needs to integrate and build upon advances in related disciplines.

In this study, the multilevel interdisciplinary theoretical paradigm was understood as a way of approaching a multifaceted qualitative research study with a clinical population. The framework developed concomitantly with the analyses included in the three papers. This is described in 3.3.1. This study’s framework of a multilevel interdisciplinary paradigm approach is illustrated in Fig.1 below. Clinical psychology of religion is at the center, representing the main theoretical approach to existential meaning-making in older people with incurable cancer. Three areas are highlighted: the existential meaning-making framework, the life span perspective and theory, and reframing. These are presented in section 2.2. In line with the hermeneutical- and contextual perspectives, palliative care is placed as the additional
dominant circle, representing the clinical context in which the study took place. For this reason, palliative care is presented first in this chapter. The three usages of palliative care, accounted for in the study, are highlighted in the figure. Research fields that were included in the three papers are placed below. This is further presented in the research review in subsections 2.3.1. and 2.3.2. Research on reframing in palliative care is presented in 2.3.6. The discipline of gerontology is connected to both palliative care and clinical psychology of religion through the conceptual framework ‘resilience repertoire’. The discipline of medical anthropology is connected to clinical psychology of religion through the definition of existential meaning-making introduced in sub-section 1.3.3. In addition, it is connected to palliative care through the cultural understanding of the clinical reality.
2.1 Palliative care

As noted in the introduction the term ‘palliative care’ was used in three different ways in the study. The first two used, palliative care as a medical discipline and as a clinical approach to patients, are presented here. Palliative care research is mainly presented in section 2.3.
2.1.1 Palliative care as a medical discipline

The emergence of palliative care as a medical discipline is related to the development of the hospice movement in England (D. Clark, 2000; Strømskag, 2012). The establishment of St. Christopher’s Hospice in London in 1967 by Dame Cicely Saunders (1996) for seriously ill and dying patients marked the beginning of a new period. Saunders initiated and led the process of developing the palliative field into an academic one, and in 1987 palliative medicine was recognized as a new medical speciality in the UK. From the establishment of the first hospice, palliative care in the following decades has spread worldwide. In May 2014, the significance of palliative care was noted by WHO, launching the first resolution on palliative care for public healthcare systems worldwide (2014 b). The European Association for Palliative Care (EAPC) (2014 a) is central in contributing to this work, aiming at developing palliative care in Europe through education, information, and research. In Norway, EAPC is connected to two organizations; one is interdisciplinary (Norsk Palliativ Forening (NPF) [Norwegian Palliative Association], 2000) and one is for physicians (Norsk forening for palliative medisin (NFPM) [Norwegian Association for Palliative Medicine], 2000). The present study is a Norwegian project stemming from the work going on in the task force and in the interdisciplinary organization. The Nordic countries collaborate on a specialized palliative medicine course for physicians. For other healthcare professionals such as nurses, social workers, occupational therapists, and physiotherapists there are higher education courses, including a master degree in clinical science of health and with a major area of study on palliative care (Høgskolen i Gjøvik [Gjøvik University College], 2015; Norges Teknisk-Vitenskapelige Universitet (NTNU)-Masterprogram [Norwegian University of Science and Technology-(NTNU) Master Program], 2015).

The national guidelines for palliative care (Norwegian Directorate of Health, 2013) constitute the main directives for palliative care in Norway. Hospital directors are requested to organize their institutions in line with the guidelines. The main objective is to improve palliative care for people with incurable cancer and to make sure there is the same high quality service throughout the whole country. This system, which is cost-free for all citizens, is included in the public healthcare system and is divided into three levels (Haugen et al., 2006; Norwegian Directorate of Health, 2013). The first is primary care, organized by and established in each community. The second level of specialized healthcare is located in somatic hospitals in each of the 19 national counties. The third level is highly specialized healthcare, which is organized in each of the five health regions in Norway. The participants in this study were recruited from the second level.
In the guidelines, palliative care in hospitals is specified as symptom-reducing and symptom-preventing treatment. This includes tumor-targeted therapies such as surgery, chemotherapy, radiotherapy, hormone therapy, and immune therapy. In addition, there are different types of non-tumor treatments, for instance liquid supply and antibiotics. It is documented that these types of treatments have a life-prolonging effect on large groups of patients. The information regarding palliative care for the participants in the study is presented in Appendix 5, Demographic data.

2.1.2 Palliative care as a clinical approach to patients

Regarding palliative care as a clinical approach, the original meaning of the term *palliation* is central (Jaiswal, Alici, & Breitbart, 2014). It is derived from Latin and the verb *palliare*, meaning “to cloack” or “to conceal” (p. 87). The noun *pallium* also refers to the cloth that is used for covering burial caskets. When these two root words are combined they suggest that a dying patient can be covered or embraced in the caregivers’ arms. Along with the mentioned growth in palliative care worldwide, different concepts have been used for describing people with incurable cancer such as ‘terminally ill’, ‘patients in end-of-life’ (Van Mechelen et al., 2013) and ‘cancer survivor’ (Payne, 2007). The WHO-definition has been criticized for being vague, leading to different understandings of the stage of life addressed by palliative care (Radbruch, 2008; Van Mechelen et al., 2013). Also, there has been a tendency in palliative care literature to focus on pathology and to connect the group to death and dying (Payne, 2007). The term quality of life is a main concept in the definition and also a core concept in palliative care research (Vivat, 2012). It is often referred to by the abbreviation QOL. In the WHO definition of QOL from 1996 spiritual concerns are included as one of six domains, thus indicating that QOL and spirituality are interrelated concepts. However, due to the special focus on existential meaning-making in the study, aspects related to QOL are not further elaborated.

Despite problematic aspects, the concept ‘palliative care’ was selected for use in this study for three reasons. First, it was the applied concept for describing treatment and care for patients with incurable cancer in specialized healthcare contexts in Norway. Second, as demonstrated in the three papers, palliative care was selected as the main research area in the cancer research field. Finally, the concept is used in the national guidelines in this particular field (Norwegian Directorate of Health, 2013). The guidelines build on a holistic approach to patients with incurable diseases, based on the hospice philosophy, and the term “total pain” from Dame Cicely Saunders (1996, p. 1600). The term is considered one of the most central...
concepts in palliative care (Strømskag, 2012). It covers the whole and complex experience for a patient with a life-threatening disease including: physical; psychological; social; and, spiritual/existential elements. Thus, the human being is understood as an indivisible entity. The WHO definition of palliative care (2014 a) builds on this understanding, and the national guidelines have integrated the definition as the main perspective. The definition was framed as the “biopsychosociospiritual” framework and the perspective used in Paper 1. The term spiritual was selected there to be consistent with the WHO definition. However, as existential is the preferred term in the study, the framework is more accurately referred to as “biopsychosocioexistential” in this study.

2.1.3 The EAPC-definition of spirituality

The development of the existential dimension in palliative care in the European countries is supported by the task force in the EAPC called Spiritual Care in Palliative Care (Nolan, Saltmarsh, & Leget, 2011). In 2011 the task force agreed upon a comprehensive and broad definition of spirituality1:

Spirituality is the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred (Nolan et al., 2011).

Due to the multidimensional nature of spirituality, implying that it is difficult to define, the task force has added that the spiritual field encompasses:

- Existential questions (concerning, for example, identity, meaning, suffering and death, guilt and shame, reconciliation and forgiveness, freedom and responsibility, hope and despair, love and joy)
- Value-based considerations and attitudes (that is, the things most important to each person, such as relations to oneself, family, friends, work, things, nature, art and culture, ethics and morals, and life itself)

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• Religious considerations and foundations (faith, beliefs and practices, ones relationship with God or the ultimate). (Nolan et al., 2011)

The definition is characterized by a broad understanding of spirituality as different concepts are used to express its complexity and multidimensional nature. This was important in two ways in the present study. The first was that the definition illustrated the importance of employing different concepts when exploring the existential domain. This was taken into account in the formulation of questions and issues in the semi-structured interview guide (Appendix 4). Through the broad approach, access to some of the heterogeneity in the participants’ reflections was facilitated. Second, in the early analytic phase for Paper I, descriptions were coded in accordance with the main concepts in the definition in order to get an overview of patterns and variations.

The last three points in the definition, that is existential questions, value-based considerations and attitudes, and religious considerations and foundations, are actually derived from the Norwegian guidelines for palliative care (Norwegian Directorate of Health, 2013). This illustrates the close collaboration between national and international healthcare professionals in the field. However, the national guidelines have not integrated the first part of the EAPC definition in the latest revised version.

2.2 Clinical psychology of religion

As noted in the introduction, the study was placed within the psychology of religion sub-area of clinical psychology of religion. The following definition was applied, developed by Van Uden and Pieper (2003) in connection with a “clinical psychology of religion” course for mental health professionals in the Netherlands:

Clinical psychology of religion applies insights from general psychology of religion to the field of the clinical psychologist. Clinical psychology of religion can be defined as that part of the psychology of religion dealing with the relation between religion, worldview and mental health. Like the clinical psychologist, the clinical psychologist of religion deals with psychodiagnostics and psychotherapy, but concentrates on the role religion or worldview plays in mental health problems. (p. 156)
In Norway there is a long tradition of employing this knowledge in pastoral care and counseling (Austad & Stålsett, 2007), whereas little attention has been given in a systematic way in clinical psychotherapeutic practice. This has gradually changed from 2000 and onwards and will be described later in this section (2.2.1). Of relevance for the study was the clarification that clinical psychology of religion applies insight from general psychology of religion, and that it deals with the relation between the domain of existential meaning-making and mental health. In this connection, the term ‘psychic functioning’ is central. Belzen and Hood (2010, p. 256) define it as a neutral term that includes psychological entities such as behaviors, feelings, experiences, and cognitions. It includes both functional and dysfunctional aspects. To investigate the relation between existential meaning-making and ‘psychic functioning’ involves dealing with diverse and difficult aspects in human life. This aspect was particularly important for the inclusion criteria in this study, see sub-section 3.6.1. For the purpose of understanding some of the phenomena involved it is necessary to reduce the complexity and multidimensional character of these types of experiences (Danbolt, 2014). A common way for understanding this type of reductionism in psychology of religion is the differentiation between methodological and ontological reductionism (Danbolt, 2014; Wikström, 1996). Scientific inquiry is always based on methodological reduction in terms of “designating the explanation of complex phenomena in terms of simpler, underlying processes” (Wulff, 1997, p. 14). When a psychological theory or empirically-based knowledge is used for answering questions about the truth or explaining the human life as a whole, the methodological reductionism has been converted to ontological reductionism. In this case, science and theory have become a type of worldview where insight into certain phenomena is lost out of sight. The understanding of reductionism in the present study has included only that of methodological reductionism.

2.2.1 The existential meaning-making framework
The content of the terms existential, spirituality, religiosity, and meaning is frequently debated in psychology of religion (P. la Cour & Hvidt, 2010; Park, 2010; Ulland & DeMarinis, 2014; Westerink, 2012; Zinnbauer & Pargament, 2005). A presentation of the different positions was not seen as relevant here, as these distinctions are not in focus. Instead, the approach to existential meaning is derived from the interaction of clinical psychology of religion as adapted by cultural psychiatry, understood as a type of meaning-making information that all persons have, influenced by cultural context, with content and function needing to be accessed (DeMarinis et al., 2011 ). For this reason the approach to existential meaning-making was
termed as pragmatic and functional as illustrated in Fig1. Research in psychology of religion that is seen as relevant for this understanding is presented here. Central in psychology of religion research is the distinction between functional and substantial approaches. Related to the latter, existential meaning-making is understood in relation to its content and how a person relates to it (Danbolt, 2014). This can include issues such as belief in a higher power, ideologies, rituals, and values. A functional approach is about understanding the role or purpose of the referred issues for the individual or a group in particularly challenging situations in life. In the current study, this was termed a pragmatic functional approach. Pragmatic meaning that the focus was on practices and experiences (Kjøll, 2015) and how these worked in daily living. The functional approach implied an exploration of the role and purposes existential meaning-making experiences served in the daily living of the participants.

In recent years research in meaning has expanded in many areas of psychology, including positive psychology, clinical psychology, and cultural psychology (Park, 2010). Central in psychology of religion research are the works by Park (2005, 2010) and Schnell (2009, 2010, 2011). Based on the work of influential theorists, among others Bonanno, Kaltman, Davis, Wortman, Lehman, Silver and Neimeyer, Park divides meaning into two basic aspects: ‘global meaning’ and ‘meaning making’. Global meaning refers to orienting systems that help us to interpret experiences and in motivation. The systems consist of “beliefs, goals, and subjective feelings” (2005, p. 297), and they are important both in ordinary daily life and in challenging situations. Beliefs refer to values and worldviews. The global goals are those we consider as most important in life. To continue with goals in areas such as relationships and health belong to this global aspect. Subjective feeling refers to “subjective sense of purpose” (2010, p. 259).

The other basic aspect ‘meaning making’ refers to is the process that takes place when there is a discrepancy between the global meaning and the implicit meaning ascribed to problematic events. The implicit meaning includes a variety of determinations, for instance questions of why the event happened and the type of consequences. In the meaning making process changes emerge in one or both types of meaning, either changing the meaning of the situation or changing the beliefs or goals. In this way the discrepancy is reduced and balance restored.

Schnell has developed The Sources of Meaning and Meaning in Life Questionnaire (SoMe) (2009). The instrument consists of 26 sources of meaning that are summarized in five
domains: vertical selftranscendence, horizontal selftranscendence, selfactualization, order, well-being and relatedness. Factor analysis of well-being and relatedness showed that they were closely linked to each other, thus they are treated as one domain. Among the 26 sources of meaning, generativity, which belongs to the horizontal selftranscendence domain, “is established as the strongest predictor of meaningfulness” (2011, p. 671). This involves investment in practices and values beyond one’s death. The finding is in accordance with Erikson’s understanding of the importance of generativity at every stage but especially in adulthood and old age (1997). This is further elaborated in sub-section 2.2.2.

Research in clinical psychology of religion in Scandinavian contexts is expanding. A treatment model in psychotherapy called the VITA-model (Modum Bad, 2015) was established in Norway in 1999 (Austad & Stålsett, 2007). Here insights from psychology of religion are applied in a systematic way. Treatment outcomes have been systematically evaluated (Stålsett, 2012). Also, there are ongoing studies that will add more knowledge to the use of psychology of religion in the model. In 2008 the Center for Psychology of Religion was established in Norway (Religionspsykologisk senter (RPS) [Center for Psychology of Religion], 2011). The center is unique in Scandinavia as is located in a hospital with somatic and mental healthcare services. This has provided the opportunity to conduct research in both fields. A conference in psychology of religion has been arranged annually. Furthermore, the Nordic Network for Research in Faith and Health (2011) was launched in 2011. The network has arranged seminars twice a year, presenting research and exchanging ideas for future research and international collaborations. A broad range of clinical populations have been studied in Scandinavian contexts, such as patients with mental diseases (Danbolt, Møller, Lien, & Hestad, 2011; Hanevik, Hestad, Lien, & Møller, 2013; Stålsett, 2012), in addiction treatment (DeM arinis, Scheffel-Birath, & Hansagi, 2009; Sørensen, Lien, Landheim, & Danbolt, 2015), with cancer disease (Torbjørnsen, 2011), patients with chronic lung diseases (Pedersen, Pargament, Pedersen, & Zachariae, 2014), and patients admitted to hospital (P. la Cour, 2008). Research from related disciplines such as sociology of religion (Ahmadi, 2006), epidemiological studies on religion and health (Sørensen et al., 2012), health science (Moestrup, 2015), and nursing (Tornøe, Danbolt, Kvigne, & Sørlie, 2014) add important insights for the field.

Researchers in all three Scandinavian countries have emphasized the need for applying concepts that are suitable for a broad spectrum of meaning-making expressions ranging from secular orientations to religious ones (DeM arinis, 2008; DeM arinis et al., 2011; P. la Cour, 2008; P. la Cour & Hvidt, 2010; Ulland & DeM arinis, 2014). Scandinavian countries have
often been described as ‘secular’ by social scientists. Both Sweden (DeMarinis, 2008) and Denmark (Pedersen et al., 2014) have been named as being the most secularized countries in the world. Research on secularization in Norway has also been conducted and discussed (Botvar, 2010; Taule, 2014). Secularization theories are criticized for being one-sided. For instance they do not capture the individual, private forms of existential meaning-making expressions and the importance of religion among immigrant populations. A dominant cultural tendency addressed in the literature is that of individualization (Botvar, 2010). Authority has been transposed from institutions to the individual. On the individual level the aspects of choices and rights have become central, while religious institutions have been seen as having less influence on people’s daily life. La Cour and Hvidt (2010) suggest a framework of concepts to describe the field of existential meaning-making in secular contexts, namely secular, spiritual, and religious. A similar structure of concepts was identified in sociology of religion research on patients with cancer in Sweden (Ahmadi, 2006): the atheist group, the theist group, and the non-theist-group. The latter group included those who believed in a spiritual being that could affect life events. In a study in a Norwegian adolescent psychiatry context therapists were asked about their understanding of the different terms: existential orientation, meaning making, spirituality and religiosity (Ulland & DeMarinis, 2014). ‘Existential’ allowed for a more open attitude to patients than the terms ‘spirituality’ and ‘religiosity’. Alternatively, ‘worldview’ was suggested.

The work of defining and delineating the concept existential meaning-making in this study was a central part of the research process from the fieldwork period through to the final analysis, illustrating the multidimensional and multifaceted character of this domain for a clinical population. Based on the hermeneutical- and contextual perspective the framework had to capture the characteristics in a particular clinical population in a particular clinical context. Further, it had to be understandable when communicating the content to healthcare professionals. Hence, the approach to existential meaning-making was shaped by the cultural context of the Inland area of Norway. For this reason the term existential meaning-making with the definition introduced in the introduction sub-section1.3.3 (DeMarinis, 2008) was selected for the study. It provided the basis for the approach to this dimension in all three papers. Extracts from the definition were applied in both Paper I and II, building on research in clinical psychology of religion in Scandinavia (DeMarinis et al., 2011; Ulland & DeMarinis, 2014). In Paper III the definition was used explicitly and linked to the existential dimension in a cultural framework model (DeMarinis, 1998, 2003; Kleinman, 1980). Also,
the broad understanding in the EAPC definition of spirituality (Nolan et al., 2011) influenced the approach as it was central in the development of the semi-structured interview guide (subsection 2.1.3).

The existential meaning-making framework was applied in three different ways through the three papers. In Paper I it was developed inductively from the material itself. Here the framework was operationalized as two concerns ‘a belief frame’ and ‘value in- and meaning in life’. In Paper II the analysis revealed that the two concerns ‘life attitude’ and ‘the relation to future and death’, were relevant as well, leading to four concerns in the operationalized existential framework. The framework was added to the SOC model for the interpretation of the data. In this way, the complexity in the existential meaning-making function was further explored. The definition of existential meaning-making developed by DeMarinis (2008) was in focus in Paper III. When placed within the cultural framework by Kleinman (1980), and further elaborated and applied to Scandinavian contexts by DeMarinis (1998, 2003), existential meaning-making was seen as essential for understanding how illness experiences were interpreted within a cultural context.

2.2.2 Life-span perspective and theory

In the study the term life-span perspective was applied in two different ways. First, it was implemented in the structure of the semi-structured guide, covering participants’ reflections retrospectively and prospectively concerning four life periods (Appendix 4). Secondly, the term represented the theory of life-span developmental psychology and the model ‘selective optimization with compensation’ (SOC), described in Paper II. As the theory is presented in Paper II, this section includes only two aspects: a core assumption in life-span developmental psychology, and two common features in the theoretical basis for the SOC model and Erikson’s life cycle theory. These were seen as central for understanding the relation between the participants’ illness experiences and the life-span perspective in the study.

The SOC model is developed by M. and P. B. Baltes and colleagues, belonging to the German research tradition (M. M. Baltes & Carstensen, 1996; P. B. Baltes, 1987; P. B. Baltes et al., 2006). The theory deals with individual development throughout the life-span. In this respect, the SOC model represents a general and overall psychological theory of the adaptation process (P. B. Baltes et al., 2006). This is an advantage in that it can be applied to develop psychological insight into adaptation processes on a diverse range of conditions as presented in sub-section 2.3.4. The core assumption regarding the nature of life-span development is that development is a lifelong process from conception until old age and
death, implying that no age period is superior to another in the management of the nature of development (P. B. Baltes, 1987). This represents a reformulation of more traditional understandings of development, focusing on maturation and advancement until adulthood and aiming at higher levels of functioning. The reformulation includes an understanding of development as more open and multidirectional, involving lifelong adaptation strategies and processes. The concepts multidirectional and multidimensional are viewed as key concepts, meaning that there are facets of plurality in the life-span development (P. B. Baltes, 1987). Furthermore, every developmental change always includes both improvement and decline. The dynamic between gains and losses is understood as constitutive for every developmental change, independent of age (P. B. Baltes et al., 2006).

Historically life-span developmental psychology was advanced through the incorporation of two strategies: the holistic person-centered, and the function-centered (p. 571). Erikson’s epigenetic scheme with eight life-span stages belongs to the first strategy. Here knowledge is generated by connecting age periods to one overall pattern or system of development. This type of approach has been identified with life-course psychology. In the second strategy, the focus is on a category of function or behaviour. Paper II has dealt with this strategy, focusing on the behavioural strategies as accounted for in the SOC model. As Erikson’s theory is a main theory within this part of psychology (P. B. Baltes, 1987), it has influenced the development of the SOC model. Two common features are highlighted below.

The first is the importance of culture and cultural factors. The SOC model builds on a biological-cultural perspective of human development. This refers to the incompleteness of development throughout the life-span, involving a continuous interplay between biological and cultural factors. The extent to which the resources in culture compensate for the biological decline is a major factor for older people with incurable cancer as the health decline becomes gradually more dominant. This means that culture has a crucial role in counteracting for loss on the individual- and group levels. If the resources in the culture are insufficient, older people’s incompleteness might be reinforced by cultural tendencies, continuously influencing their adaptation process in daily living. In this connection Baltes and colleagues describe how “the culture of old age” is undeveloped when compared to that of younger age groups (2006, p. 575). The same point has been addressed by Erikson (1997). The individual life-span or life-cycle cannot be understood separate from its social context. He argues that western culture is “lacking a culturally viable ideal of old age, our civilization does not really harbor a concept of the whole of life” (p. 114). As a consequence there is a cultural lack of knowledge concerning how to facilitate and strengthen older people’s resources, including
their wisdom. Instead there might be social patterns of disregard or neglect. In this study the impact of culture was elaborated upon in Paper III. Here the theoretical frame of reference was from medical anthropology, providing a cultural understanding of the existential dimension.

The second feature is that of generativity and wisdom. In Erikson’s theory (1997) these are related to growth in adulthood and old age. The dominant theme in old age is termed integrity versus despair. Integrity means wisdom, which is tied to the acceptance and management of the generational passages of life and life’s finitude. Previous life stages shape the content of the themes. Generativity versus stagnation belongs to the adulthood period. The need to “maintain grand-generative function” (p. 63) is essential in old age. Essential in generativity is that of care: “a widening commitment to take care of the persons, the products, and the ideas one has learned to care for” (p. 67). In Paper II this was described both in sub-observation 2, continuation of life goals, and in sub-observation 3, self-transcendent behavior, reaching outside oneself and giving help to others.

Life-span research has shown that wisdom becomes increasingly difficult towards the end of life, with hard-won acceptance and mastery of decline and loss (P. B. Baltes et al., 2006). Despite the challenges, the application of the SOC model can be useful for the identification of meaningful domains and goals that are related to generativity and wisdom in older people.

### 2.2.3 Reframing

As noted in sub-section 1.3.4 in the introduction, the understanding of the term reframing is related to the psychotherapeutic tradition as presented by the Finnish psychotherapist Mattila (2001). In psychology of religion Pargament has included the terms “religious reframing” (1997, p. 221) in religious coping theory and “spiritual reframing” (2007, p. 272) as a part of spiritual integrated psychotherapy. Religious reframing means that “beliefs about events, oneself, and the world are realigned with each other and placed in a new perspective” (1997, p. 221). Spiritual reframing means “to place negative events into a larger, more meaningful, often more hopeful and benevolent context” (2007, p. 272). These definitions are similar to the one presented by Mattila in the sense that the aspect of changing the interpretation of a situation into a new and more meaningful perspective is central. What differs is related to the term reframing itself, being connected to the terms religious and spiritual in Pargament’s theory.

Mattila (p. 35) describes how reframing can be understood from different perspectives: “categorization, concepts, analogies, metaphors, ‘seeing as’, dialectics and interpretation”.

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Categorization, concepts and metaphors were seen as particularly relevant concerning the understanding of reframing in this study.

Categorization is a fundamental cognitive activity, taking place in every dialogue. Through the sharing and expression of words the world is continually classified into categories. Categories consist of objects that are equal in meaning. According to a frame view of concepts, based on Kant, Bartlett, and Piaget, the information stored in the categories must be included in concepts. The conceptualization serves the following tasks: “comprehension, prediction, and action” (p. 15). Regarding older people in this study’s sample it was probable that they tried: to comprehend the cancer diagnosis and its implications, to predict how it would affect daily living, and to find ways of interacting with the situation. When sharing their illness experiences the concepts functioned as mental structures, containing knowledge about how to deal with this particular situation.

Categorization serves two cognitive functions. The first one is that the flow of information is reduced, thus helping to simplify and filter the world. The second function is that categorization opens up to information that lies beyond the actual situation. This is because the category is linked to a library of information, meaning concepts, and terms in our memory. The library includes information about how to understand and relate in the actual situation. With this knowledge the study participants’ reframing was better understood. When they reframed the illness experiences, they opened up the library of information in their memory, while also simplifying and filtering the world. Thus, the reframing involved complex cognitive functions.

For the understanding of metaphor, Mattila builds on the research tradition in philosophy and linguistics. In this tradition, particularly based on Black’s interaction theory, metaphor is understood both as a process “by which new perspectives of the world come into existence,” and as a product, “a perspective or frame, a way of looking at things” (p. 18). While a process metaphor represents a cognitive system where associations and implications of a particular situation or thing are filtrated and transformed. Through the interaction between the current situation and the system, certain aspects are emphasized and addressed, thus creating new connections in our perceptions of the world. Examples of metaphorical expressions as products are for example “seeing things in a new light, and “new ways of looking at things” (p. 19). Inherent in the understanding of metaphor as a process is the knowledge about the concealed characteristics of aspects. A metaphor can never capture every aspect in human experiences. Thus, the acquired perspectives are always incomplete. The metaphor “the strong
link to life in the present" was considered to be the most essential metaphor for the participants in this study. This is elaborated on in 5.1.1.

2.3 Research review

The research review was carried out in three stages in the research process: during the preparation for the data collection, updates during the writings of Paper I, II, and III, and for the final writing of the overview of the study. The second stage involved the most comprehensive reviews. In all three stages a health librarian guided the identification of MESH-terms and text words. The following databases were included in every review: Medline, PsychInfo, CINAHL, SveMed, and Bibsys. In addition, palliative care research in Norway was checked regularly, more specifically the national registry of cancer (Cancer Registry of Norway, 2014), the four regional centres for palliative care (Association], 2014) and cancer/palliative care associations (Norsk forening for palliative medisin (NFPM) [Norwegian Association for Palliative Medicine], 2000; Norsk Palliativ Forening (NPF) [Norwegian Palliative Association], 2000). The time period varied from 1980 and onwards, to 2005 and onwards, depending on the amount of research in the existing fields. The review process included the following four steps: 1. reading the title and keywords, 2. if similar or corresponding text words, reading the abstract, 3. if similar aim and/or methods and/or results, reading the article, and, 4. if in doubt, reading the article.

In the following sub-sections the main research fields are presented. These include: patient’s experiences of living with incurable cancer, spiritual care in palliative care, resilience, the SOC model in qualitative studies, research on culture in clinical contexts, and reframing in palliative care research.

2.3.1 Patient’s experiences of living with incurable cancer

Due to the limited amount of research on older people in palliative care it was necessary to broaden the research review in Paper I, by including studies on younger age groups and gerontology research. The research on patients’ experiences was presented under the headlines ‘experiences of being connected to life’ and ‘experiences of oscillation movement’. Some studies formulated the experiences of being connected to life explicitly: “links to life” (Sand, Olsson, & Strang, 2009); “latching onto life a bit longer” (Sæteren, Lindström, & Nåden, 2010); and, “connections to life” (K. La Cour, Josephsson, & Luborsky, 2005). In a Norwegian study (Devik, Enmarker, Wiik, & Hellzén, 2013) on older people aged 71-75 living alone and receiving life-prolonging chemotherapy, a life-oriented attitude was present
despite the suffering. Several of the studies reported both aspects, addressing the complexity and contrast in the experiences. For instance, in a Norwegian study Sætheren (2006) interviewed patients aged 47-76 and nurses working in palliative care in specialized healthcare contexts. The focus was on the struggle between health and suffering, experienced as a dialectic movement formulated as “a struggle for life in the veil of pensiveness”. In a Danish study Rydahl-Hansen (2005) interviewed patients aged 40-74 about suffering, finding that the suffering was experienced as a growing unpredictable existence. In a qualitative systematic literature review on experiencing cancer in old age (Hughes et al., 2009, p. 1139) a similar duality was found, described as “to live in a perpetual state of ambiguity”. This included social withdrawal, diminished identity, suffering, and a sense of disintegration on the one hand. On the other, it involved balancing experiences of comfort and strength from others and from within the self. In summary, older people with incurable cancer were found to be “resilient and vulnerable” (p. 1139).

Three studies by the same main author, K. LaCour and colleagues, were identified, focusing on the daily living of people with incurable cancer in Denmark. Engagement in creative activity strengthened daily life connections for older people aged 70-79 in a nursing context (K. La Cour et al., 2005). Thus, they engaged more actively while facing the uncertainty of the disease trajectory. Meaning-making related to activities that are important in everyday life for handling an incurable cancer illness was also explored (K. La Cour, Johannessen, & Josephsson, 2009). The participants were between 39-67 years of age and the meta-narrative was “saying goodbye in a good way” (p. 472). The good way seemed to be connected to the narrative “I am healthy although I am sick” (p. 473), thus being oriented towards health-associated aspects in life while also dealing with the illness. Finally, the possibilities in daily activities were in focus in people aged 39-67 (K. La Cour & Hansen, 2012). The findings revealed that special attention was paid to sensory experiences such as gardening and making food. To make the best out of the time that was left was central.

2.3.2 Spiritual care in palliative care

Two reviews were carried out concerning qualitative studies in palliative care using spirituality and related terms such as existential, meaning, belief, and religion/religious. The first review was in the beginning of the research period and the second towards the end. In the first review the time limit was from 2005 to November 2011. This was due to the increasing amount of research from 2000. For instance, a literature review found 850 possibly relevant references in the time period 2001-2007 compared to 216 in the time period 1996-2001.
This situation was in contrast to that in Norway where the amount of research has been scarce (Magelssen & Fredheim, 2011; Sørensen et al., 2012). A variety of terms and definitions were in use to describe the existential domain. The most dominant were spirituality, existential, and hope. In a meta-study on spirituality, close relationships were identified as a dominant and integral part of spirituality (Edwards, Pang, Shiu, & Chan, 2010). Dignity care was identified as a large research area in palliative care (Chockinov, 2007). The term has been used synonymously with spiritual care and psychosocial care. It has also been explored in the care for older people in nursing practice (Anderberg, Lepp, Berglund, & Segesten, 2007). Since the framework has been intended for use by healthcare professionals (Chockinov, 2007) it was not seen as relevant for the study.

The next review was on palliative care research on the existential domain in Scandinavia. Studies including patients with other chronic diseases were excluded. The time limit was from 2000 to 2014. A variation of terms and definitions was also the case here, including: existential issues/crisis (Browall, Melin-Johansson, Strang, Danielson, & Henoch, 2010; Sand et al., 2009; Sand & Strang, 2006), spirituality (Norum, Risberg, & Solberg, 2000; Strang & Peter, 2001), hope (Benzein, Nordberg, & Saveman, 2001; Esbensen & Thomsen, 2011), suffering (Rydahl-Hansen, 2005; Sæteren et al., 2010), and meaning making (K. La Cour et al., 2009). The majority of the studies were from Sweden. Methodologically the research has been dominated by qualitative methods, using focus groups and interviews. Attention has been given to three different groups in clinical contexts: patients, caregivers, and health care staff. Existential was the term most frequently used. Incurable cancer represented an existential threat for the patient that had to be dealt with (Sand et al., 2009; Sand & Strang, 2006; Strang & Peter, 2001). Theoretically, existential philosophy and existential psychology by Yalom (1980) with the four concerns: death, freedom, existential loneliness, and meaninglessness, were seen here as central. This was based on cultural analysis, finding that it corresponded well with the experiences of patients and caregivers in secular contexts in Sweden. Furthermore, the research showed that the healthcare professionals’ opinions about important existential questions for the patients were similar to the existential concerns from Yalom (Browall et al., 2010). Through this type of clarification of the existential domain, healthcare professionals received insight into how to identify issues and support patients and caregivers in their existential crisis.
2.3.3 Resilience

An overview volume of gerontology research on resilience in aging (Resnick, Gwyther, & Roberto, 2011) was a central resource. In addition, a literature review on resilience in older people in palliative care was conducted. The findings were presented under the headlines ‘resilience in gerontology research’ and ‘resilience in older people in palliative care research’ in Paper I. Different understandings of resilience have been used (Allen, Haley, Harris, Fowler, & Pruthi, 2011), indicating that resilience in aging is multifaceted. Identification of responses to stressful life events has shown a variation in responses and resulting consequences for their lives, perhaps indicating different degrees of resilience (Hardy, Concato, & Gill, 2002). Older people experience fewer adjustment problems and exhibit more resilience than younger age groups when dealing with chronic illnesses, particularly regarding resistance and psychological recovery (Rybarczyk, Emery, Guequierre, Shamaskin, & Behel, 2012). Resilience has been identified as a key factor in ‘survivorship research’ in people with incurable cancer (Rowland et al., 2013, p. 2101).

To apply a definition that corresponded with the participants’ responses to the adversities was seen as important, thus the process-oriented framework ‘resilience repertoire’ from gerontology was selected (P. G. Clark, Burbank, Greene, Owens, & Riebe, 2011). The framework is understood as a “supply of skills and resources” (p. 53), being activated in order to reduce the negative consequences of difficult events. In some cases, the activation might lead to growth and development. This aspect of adding growth to the understanding of resilience has also been addressed in palliative care research (Pentz, 2008). Also, a comprehensive understanding of resilience is argued for (Nakashima & Canda, 2005) in order to get a holistic overview of the process. In Paper II the conceptual framework “resilience repertoire” was taken a step further, linking it to the restoration understanding of resilience in the SOC model. Here a comprehensive understanding was suggested, involving both restoration and growth dimensions.

2.3.4 The SOC model in qualitative studies

An extensive review was carried out for Paper II in gerontology and geriatrics, and combined with palliative care research. The inclusion criteria were: qualitative articles on older people’s experiences of living with an incurable disease, applying a life span approach, or focusing on continuity or resilience or chronic illness in old age. The databases Embase and Ahmed were added to the included databases, and the time limit was extended to 1987 for most of the bases. The SOC model was identified in the review (M. M. Baltes & Carstensen, 1996; Baltes
P. B. & M. M., 1990; P. B. Baltes, 1987, 1993; P. B. Baltes, Baltes, Freund, & Lang, 1999; P. B. Baltes et al., 2006), and presented under the headlines ‘Resilience in aging’ and ‘Selective optimization with compensation (SOC)’. The review also identified studies applying the SOC model on clinical populations. These were placed under the headlines ‘The SOC model in chronic illness research’ and ‘The SOC model in qualitative studies’ in Paper II.

Concerning the first headline, the following patient groups were identified: with multiple sclerosis (Wilhite, Keller, Hodges, & Caldwell, 2004, p. 185), with arthritis (Janke, Jones, Payne, & Son, 2011), in stroke rehabilitation (Donnellan, Hevey, Hickey, & O’Neill, 2012; Donnellan & O’Neill, 2014), with depression (Weiland, Dammermann, & Stoppe, 2011), older patients with chronic pain (Alonso, López, Losada, & González, 2013), and older people with late-stage cancer (Rose, Radziewicz, Bowman, & O’Toole, 2008). In this research the SOC model was found to be a basic framework for investigating how people adapt and manage certain difficulties, useful for healthcare professionals in order to guide people with chronic illnesses in finding ways to identify, select, maintain, and maximize certain behaviors and personal goals. Activation of the SOC-strategies was seen as a possible explanation for low levels of psychological distress in a Norwegian quantitative study, including people aged 75 and older receiving home nursing care, (Thygesen, Saevareid, Lindstrom, & Engedal, 2009).

Concerning the next headline the review identified qualitative studies where the SOC model has been used as an analytic tool, indicating that it is applicable in this type of research (Janke et al., 2011; Rush, Watts, & Stanbury, 2011b; Wilhite et al., 2004). In a review of successful aging models, SOC was evaluated as an important, useful, and promising model for empirical studies (Ouwehand, de Ridder, & Bensing, 2007).

Other theories were identified on life-span and aging as well, among others: continuity theory, socioemotional selectivity theory, theory on gerotranscendence, and social integration theory. However, the SOC model was seen as the most relevant one for this study due to the operationalized framework and the number of studies conducted.

2.3.5 Research on culture in clinical contexts
A medical anthropology model developed by Kleinman was selected as the theoretical frame of reference for Paper III. The literature review had no time limit since his main book was published in 1980. Inclusion criteria: the concepts of culture/ cultural analysis/ethnicity in healthcare in Western countries, cultural analysis/ ethnicity in palliative care, Kleinman, and relevant research in Scandinavia and Norway.
Regarding research in palliative care the time limit was set to 2005 and onwards. A review in Google Scholar was added, using Kleinman and the title of the main book (1980) and reviewing cited articles and palliative care. Here the text word ‘end-of-life care’ proved to be more specific than ‘palliative’, leading to central background information about the role of culture in palliative care settings (Gysels et al., 2012a; Gysels et al., 2012b; Harding & Higginson, 2010). Selman and colleagues (2014) identify and begin to address the neglect of spiritual and cultural aspects in palliative care contexts. Furthermore, they emphasize the urgent need for guidelines integrating the cultural aspects of palliative care.

The approach to culture in mental health clinical context research in Norway linked cultural- and existential meaning analyses (DeMarinis et al., 2011; Ulland & DeMarinis, 2014). Existential meaning-making is understood as fundamental for how cultural interpretations of health and illness are perceived and practiced. The approach to gaining this type of information is in line with the understanding of culture in the latest edition of the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association DSM-V, 2013).

The works by Kleinman and colleagues were presented under the headline ‘A cultural understanding of the clinical reality’ in Paper III (1980, 1992, 2013; 2006). The cultural framework which has been further elaborated as five dimensions, and adapted to palliative care in a Scandinavian context by DeMarinis (1998, 2003) was also presented here. The review identified studies in palliative care that have integrated Kleinman’s basic assumption of illness and disease in clinical contexts (Crawley, Marshall, Lo, & Koenig, 2002; Gysels et al., 2012b; P. Hall, Stone, & Fiset, 1998; Payne, 2007; Surbone, Kagawa-Singer, Terret, & Baider, 2007).

2.3.6 Reframing in palliative care research
A review was conducted towards the end of the study on reframing in palliative care research. There was no time limit. The database Embase was added to the review. Four themes were identified as closely related: coping with uncertainty, meaning constructions, hope, and storytelling.

Reframing has been identified as one of three overarching analytic themes in a qualitative systematic review on men’s experiences of living with prostate cancer (King et al., 2015). The two other themes were uncertainty and timing of support. In the systematization of the findings reframing was strongly connected to uncertainty: “reframing arises as means of coping with uncertainty” (2015, p. 11). The theme of uncertainty has emerged both in this
particular research (Bailey, Wallace, & Mishel, 2007) and in literature on long-term illnesses more widely. Mishel (1990) has developed a theory of uncertainty in illness, explaining how people manage uncertainty by cognitively processing their illness experiences and structuring meaning from them. A basic assumption in the theory is that uncertainty belongs to the natural rhythm of life. As such it is not to be resolved. Rather, it has to be accepted in ways that allow for new possibilities to emerge. Thus, a probabilistic view of life is suggested. For people with chronic illnesses the constructions of meaning might involve countless possibilities and ways of adapting to difficult life circumstances.

Meaning constructions have been investigated in a qualitative study from Australia (Lethborg C., Aranda S., Bloch S., & D., 2006). People with incurable cancer aged 36-78 were interviewed about how they experience and apply meaning. The understanding of meaning was related to three theoretical concepts: assumptive world from Janoff-Bulman, sense of coherence from Antonovsky, and meaning-based coping from Folkman and Lazarus (p. 29). Among these, the latter appears to be perhaps the most basic for reframing. Meaning-based coping holds that when people experience events causing disruption in previous views of life, this might lead to reappraisal of their circumstances in order to adjust the meaning to the actual situation. In addition, people may ascribe meaning to their daily living in ways that enhance positive feelings despite difficulties. All the participants applied meaning-based coping and positive reappraisal to focus their attention on daily events. The patients moved in and out of three domains, forming an adaptation process towards coherence and sense of self: “experiencing the reality of advanced cancer (assumptive world), responding to the impact of advanced cancer (sense of coherence), and living fully with continued meaning (meaning)” (p. 35). Positive reappraisal based on coping theory has been identified in other studies as well (Duggleby et al., 2012; Redinbaugh, Baum, Tarbell, & Arnold, 2003).

A meta-review of qualitative studies has investigated hope experiences of older people aged 60 and older with chronic illnesses (Duggleby et al., 2012). Incurable cancer was one of the included illnesses. On the basis of the review hope was defined as “desirable (wanted) possibilities” (p. 1219). A main finding underlying the definition was that of positive reappraisal, including both re-evaluation of hope during the illness trajectory and seeing positive possibilities. For the understanding of the reappraisal, coping theory from Folkman and Lazarus was applied. In a qualitative study from Canada (Sze et al., 2006) including patients with brain tumors aged 50-72 and caregivers, the term “reframing hope” was seen as central when talking about the expectations of radiotherapy treatment. This involved respecting the need for hope while also giving realistic information. In this way, the patient
was helped to adjust to the situation. However, the term was not defined or further discussed. A Swedish qualitative study (Salander, Bergenheim, & Henriksson, 1996) found that patients with brain tumors aged 18-70 were able to use cognitive mechanisms to create protection and hope. Reframing was identified as one way of handling the bad information.

Storytelling has been investigated in a Norwegian study including 51 participants aged 43-95 (Synnes, 2012). The stories were conducted in courses in writing and storytelling in palliative care, and the main focus was on narrative identity. The findings revealed that in most stories the illness was in the background, while what was considered as “the good life” was more in the foreground. Essential in “the good life” were: “solicitude: giving and receiving; belonging in particular places, living in nature; gratitude of life; existential and aesthetic aspects; to stand up for others, to stand up for oneself, and to be healthy” (p. 306). The storytelling was seen as a meaning-making process, being vital for how the participants constituted themselves. In many stories this was a way of holding on to connection or direction, representing a response to the threats from the illness.
3 Research design and methods

In this chapter the research design and the methods in the study are presented. The chapter is structured into two main sections. In the first section, 3.1-3.4, the presentation of the ethical approval for the study and ethical issues, and the research question in relation to three methodological levels are provided. In the second section, from 3.5 onwards, the focus is on methods for data collection and data analyses.

3.1 Ethical considerations

The study was approved by the Regional Ethical Committee for Medical and Health Research Ethics (REC), South-Eastern Norway (reference number 2011/920) (Appendix 2) and The Privacy Protection Department at Oslo University Hospital (Appendix 3). Initially, REC considered the approval as unnecessary, arguing that the study by focusing on the existential dimension was outside of medical and health related research, thus not included by the health research law (Stiftelsen Lovdata [Law Institution], 2013). The decision was appealed because the study was seen as health-related. In order to really understand the illness experiences of older people, information about the clinical context they belonged to was of relevance. This would include both negative and positive experiences with healthcare professionals. Thus, the study had the potential of contributing new knowledge for healthcare professionals, which in turn would benefit older people with incurable cancer. Also, including sensitive information such as psychological and social matters was important and in accordance with the main holistic perspective on palliative care accounted for in the Norwegian guidelines (Norwegian Directorate of Health, 2013).

The ethical aspects of including patients in palliative care in research is widely discussed in the literature (Gysels et al., 2013) since the patients often have fluctuating symptoms, sometimes leading to abrupt worsening of the health condition. In general it is not seen as unacceptable to perform research on this group of patients (Grønvold & Sjøgren, 2007; Gysels et al., 2013; Møsterstedt & Landmark, 2009). Rather, it is described as an ethical obligation due to the lack of knowledge about what constitutes quality in treatment and care for this patient group (Møsterstedt & Landmark, 2009). Also, insights into demographic and epidemiological aspects are needed (Grønvold & Sjøgren, 2007). The EAPC has included recommendations on palliative care proposed by the European Council (2003). Four principles are seen as important for healthcare professionals: respect for autonomy, beneficence, non-maleficence, and justice.
For the participants in the sample, autonomy was particularly relevant in relation to informed consent. Since the healthcare professionals gave the first information the probability of abstaining from participation was greater than if it had been given by the researcher. After inclusion, the participants were informed both in the information letter and verbally about the option to refrain at any stage. For the majority, the informed consent was signed right before the interview started. In this situation the health situation of the participants, whether or not they were suitable for being interviewed, was considered. Two interviews were canceled as they were about to start because of serious health problems. Hence, the informed consent was a continuous process in order to ensure sensitivity to any types of changes in the participant. This aspect has been included as one of 16 recommendations for ethical issues in palliative care (Gysels et al., 2013).

Another recommendation is that of a sensitive approach to recruitment when incorporating wide inclusion criteria. Empathy throughout the recruitment process is required, ensuring the voluntary nature of participation and receptiveness to the participants’ level of understanding. This type of approach was central in the recruitment process in the study. The low level of recruitment from the beginning indicated that time was needed to establish the close collaboration between the recruitment sites and me as a researcher. A common understanding of the inclusion criteria was needed.

Of relevance for the principles of beneficence and non-maleficence was that the recruitment sites were responsible for the follow-up of any participants who might receive psychological after-effects from being interviewed. This was clarified with the head nurse or deputy in advance with an agreement to make contact by telephone. None of the participants indicated a need for such help. Rather, some stated the opposite, reporting that they felt affirmed. Others saw the interview as meaningful, providing an opportunity to contribute their experiences to others. In one case, the current author’s professional background from the mental health field was relevant. The head nurse was contacted after one of the interviews, when a suggestion for a referral to hospice was made due to identified long-lasting psychological problems.

3.2 Research question type, phenomena, and empirical material
According to Belzen and Hood (2010) there is a tendency in psychological research to connect the term empirical to quantitative methods, seeing them as superior to qualitative approaches. This view is untenable from a philosophical point of view. The choice between
methods is both based on the object or phenomenon of the research and what type of knowledge the researcher seeks to acquire. Due to the type of research question, the phenomena to be researched, and the nature of the empirical material to be gathered in the study, it was necessary to include methods that allowed for interpretative and process-oriented approaches to the text material. The return to the original Aristotelian sense of ‘experience’ and ‘data’ was central for understanding the hermeneutical tradition in psychology as empirical (Belzen & Hood, 2010, p. 263). The Greek word *empereia* is translated into the word *experentia* in Latin. In the course of scientific development in modern times the word has lost its original meaning and been co-opted to signify only a limited set of scientific methodological practices. Correspondingly, the original meaning of the word ‘data’ “derived from the Latin *datum* as that which is given”, was linked to *factum* which originally means “that which is made” From a hermeneutical perspective ‘data’ means to investigate what is already there as opposed to something that is made in a controlled setting. Hence, the return to the original meanings of ‘empirical’ and ‘data’ constituted the basis for investigating experiences in the real world of and reported by the participants.

The research question in this qualitative study was: *How do older people experience living with incurable cancer in daily living - with special reference to the psychological functions of existential meaning-making experiences?* Two aspects were included in the research question; the group of older people’s experiences in general and the psychological functions of their existential meaning-making experiences in particular. The objective, as presented earlier, was: to describe how they experience living with incurable cancer, and to explore and understand, primarily, the psychological functions of their existential meaning-making experiences. Accordingly, the phenomena were: *older people’s ways of making meaning of their cancer illness experiences, and the psychological functions of their existential meaning-making experiences.*

For answering the research question, the research design, data-gathering- and data-analysis methods were understood in relation to two methodological levels as illustrated in Fig 2. Due to the focus on understanding meaning phenomena the first and overall level was hermeneutical, related to the hermeneutical tradition in psychology (Belzen & Hood, 2010). Here understandings of the hermeneutical circle and the hermeneutical situation from Gadamer (2011) provided the main concepts. The second level concerned inductive and deductive analytical approaches (Creswell, 2009), each applying theory differently. The inductive approach was applied in Paper 1, focusing on the first part of the phenomena: *older people’s ways of making meaning of their cancer illness experiences.* Here the inductive
analytic strategy “editing analysis style” using “systematic text-condensation” was employed. The strategy is based on Giorgi’s phenomenological descriptive method (1985, 2009) and has been modified for qualitative research by Malterud (2011, 2012). The deductive approach with the analytic strategy “template analysis style” was employed in both Papers II and III, focusing on the second part of the phenomena: the psychological functions of their existential meaning-making experiences. The usage of these two strategies permitted a double reading of the interview material, providing for a deeper and more thorough analysis of the data. The double reading is illustrated in Fig 2 with the horizontal arrows, showing that Paper II was built upon the results from Paper I, and Paper III was built on the results from Papers I and II. The main concept in the three papers was the expressed illness experiences of the participants. It contained the type of knowledge the study sought to explore and understand. As noted in 1.3.1 the combination of the terms illness and experience allowed for exploring psychosocial processes and patterns in existential meaning-making within the micro worlds of older people with incurable cancer. The illness experiences were materialized in the form of verbal expressions, collected from the semi-structured interviews. The content represented subjective data collected, at the interview time, in each participant’s life as incurably sick with cancer.
**Fig. 2 Research design and methods**

**Level 1**

The hermeneutical perspective

The hermeneutical circle and the hermeneutical situation

(Gadamer)

(Belzen/Hood)

**Level 2**

Multilevel interdisciplinary paradigm filter

The inductive approach

The deductive approach

Double reading of the interview material; the expressed *illness experiences* of 21 older people with incurable cancer

**Paper 1**

**Editing analysis style/systematic text-condensation**

Four steps: to obtain a comprehensive perspective of the text, to identify content categories, to condense meaning, and to summarize the significance of the content.

(Giorgi, Malterud)

**Paper 2**

**Template analysis style**

Three steps: identify units, sort categories, connect to the text- corroborating/legitimating

(M Malterud)

**Paper 3**

**Template analysis style**

Three steps: identify units, sort categories, connect to the text- corroborating/legitimating

(M Malterud)
3.3 Level 1: The hermeneutical perspective

On an overall level the concept of analysis is approached and related to the realm of philosophy, and more specifically to hermeneutics as accounted for by Gadamer (2011). Hermeneutics is about understanding and interpreting text material. Gadamer formulates the task in hermeneutics in the following way:

“When we try to understand a text, we do not try to transpose ourselves into the author’s mind, if one wants to use this terminology, we try to transpose ourselves into the perspective of the other within which he has formed his views. But this simply means that we try to understand how what he is saying could be right. If we want to understand, we will try to make his arguments even stronger” (2011, p. 292).

The task is merged in the movements in the hermeneutical circle and determined by some characteristics in the hermeneutical situation. Both concepts are presented below. When applied in the study the task was understood as twofold: 1) to understand the participants’ perspectives from their vantage points, and 2) to make their views stronger by making them more comprehensible and distinct. The first task corresponded to the objective in the study. It was accomplished by beginning with the inductive (close to the data) approach, and letting the findings from the phenomenological analysis guide the direction for the deductive (theory-inspired) approach. To give reasonable, systematized, and coherent interpretations of the participants’ illness experiences were central in this task. Based on these interpretations, the second task implied bringing a greater understanding of psychological and psychosocial processes and cultural patterns. The hermeneutical task clarified how the intended meaning of in-depth understanding was perceived in the study.

The hermeneutical perspective here is also inspired by the elaboration by Belzen and Hood (2010) on the hermeneutical tradition in psychology with the main emphasis on Gadamer’s hermeneutics.

3.3.1 The hermeneutical cycle

The hermeneutical circle represents a way of interpreting text material where understanding develops though the circular movement between the partial and the whole. According to Gadamer (2011) the main point of departure is the preunderstanding, containing an intuitive understanding of the whole. When related to the study, the process moved from the preunderstanding to insight in parts, which in turn affected the understanding of the interview
material. The acquired understandings both challenged and contradicted the presumptions. Due to the cyclic and never-ending character of the interpretation process, the acquired understanding was provisional, incomplete, and limited (Belzen & Hood, 2010). Based on these movements the meanings of the participants’ experiences were transposed from belonging to their subjectivity to finally being intelligible in themselves (Gadamer, 2011). During this gradual process, there was a need to go back to the text material repeatedly to identify reasons for the partial meanings. Towards the end of the interpretation process, this need decreased. The partial meanings were connected together into meaning units, subsequently followed by overall categories, observations, and themes. Due to this type of process, the meaning could be shared and became comprehensible to others. Gadamer describes this task in hermeneutics as “to clarify the miracle of understanding” (p. 292).

The preunderstanding in this study was influenced by three factors: professional background, preparatory work in the field contexts, and the role of theory. In terms of professional background, the author is a psychiatric nurse holding a master’s degree with specialization in psychology of religion. My clinical work has been in the mental health field, in psychodynamic-oriented psychotherapy with adults aged 18-65, for almost 20 years. Thus, to seek in-depth understandings was seen as central. Another factor was having lived and worked in the recruitment area. The influence from the wider Norwegian culture affected the selection of the concept existential meaning-making as it was seen as easier to comprehend for healthcare professionals than the term ‘spirituality’. In light of my professional background, the research field in the study was new in every respect. Not only was cancer and palliative care new areas, so also was the age group of older people. Thus, there were assumptions that needed to be corrected. One of the assumptions was that few older people were receiving chemotherapy treatment, and that the ones who did were too sick for engagement in relationships and activities. Another was that they would be preoccupied with the problematic sides in their life situation. For this reason a preparatory time in the field context, the second factor, was organized. This is presented in 3.5.

The third factor was related to the role of specific knowledge in the preunderstanding phase. Central were two conceptual frameworks that guided the questions and issues in the semi-structured interview-guide. The frameworks were the WHO-definition of palliative care (2014 a) and the EAPC –definition of spirituality (Nolan et al., 2011), both encompass a broad approach to the participants’ illness experiences in their daily life. This is presented in 3.6.2.
3.3.2 The hermeneutical situation

Gadamer emphasizes the significance of historical consciousness also framed as “the hermeneutical situation” (2011, p. 301) when interpreting text material. This consciousness involves being aware of the fact that in scientific inquiry, history is always at work. This is because the investigation takes place within a certain moment and place in history. In this connection Gadamer formulates the efficacy of history as follows: “It determines in advance both what seems to us worth inquiring about and what will appear as an object of investigation” (p. 300). This type of awareness may lead to questions that are more precise than if the historical consciousness is forgotten. The awareness is related to some characteristics in the hermeneutical situation of which four were seen as relevant for the study, both prescribing and limiting the possibilities for understanding. First, due to the power of history in every situation, an all-encompassing understanding of a situation can never be fully achieved or completed. For this reason the acquired understanding in the study was provisional, partial, and incomplete. The participants were interviewed at a particular point in time during their period as patients in palliative care in specialized healthcare contexts. Thus, their illness experiences were both revealed and shaped in this situation.

Second, the hermeneutical situation implies that to stand outside a situation and take an objective stance, and seek objective knowledge is impossible. To be within the hermeneutical situation means both to affect and to be affected by the actual situation. This was particularly noticeable when the circumstances were unpredictable or distracting. For instance, one interview at the hospital had to be moved in the last minute to a room without windows, only furnished with a big table and chairs. Several times during the interview a bell was ringing, reminding us that we were in a hospital. This was a stressful situation where it was difficult to concentrate for the current author. How this affected the actual knowledge derived from this interview is difficult to determine. From a hermeneutical perspective it is in fact impossible to fully determine such in light of the third characteristic in the hermeneutical situation; self-knowledge.

As human beings marked by our history, self-knowledge can never be complete. For this reason it is impossible to obtain a full overview of presumptions and subjective intentions. As described by Gadamer (2011) the incompleteness is not related to deficiency in reflection. Rather, self-knowledge always emerges from what is historically pregiven, and from this condition, subjective intentions and actions are formed.

Finally, the fourth characteristic is “horizon”, understood as “the range of vision that includes everything that can be seen from a particular vantage point” (p. 301). Essential in the
hermeneutical situation are the possibilities for expanding one's vision beyond what it was
tied to in advance. When this is applied to the thinking mind it means that the mind is not
limited to what is nearby but seeks to understand what is beyond it. Applied to the study, this
meant to work step by step in the analytic phase from identifying categories and themes to
connecting them into overarching patterns, processes, and observations. In particular
this was made possible through the double reading, which is presented below.

3.4   Level 3: Inductive and deductive approaches in the double reading of the
data
The inductive- and deductive approaches refer to the use of and relationship to theory in
analyzing data. Malterud applies a figure from Miller & Crabtree (2011, pp. 95-96) with three
strategies for analyzing qualitative data. The placement and role of theory is here central for
differentiating between the strategies. Two of the strategies were applied and combined in the
study as illustrated in Fig 2: the “editing analysis style” in Paper I and the “template analysis
style” in Papers II and III.²

The “editing analysis style” is based on descriptive phenomenology from Giorgi (1985,
2009). Giorgi defines description as “the use of language to articulate the intentional objects
of experiences” (2009, p. 89). It involves articulating the subjective and experiential world of
the participants as precisely as possible. The aim is to seek adequacy, in terms of thick
descriptions about the presented phenomena. Malterud has modified the “editing analysis
style” for qualitative medical research, and termed it “systematic text-condensation” (2011,
2012). It comprises four analytic steps as seen in Fig 2: to obtain a comprehensive perspective
of the text, to identify content categories, to condense meaning, and to summarize the
significance of the content. The last step also involves connecting the findings back to the text
in order to see if concepts can be developed. Also, the findings are compared to relevant
research and theory. The strategy is further described in 3.7.4.

The “template analysis style” (Malterud, 2011) belongs to the deductive approach, also
framed as theory-driven or theory-inspired analysis. Here theory and conceptual frameworks
are applied as lenses for the interpretation of the data. As illustrated in Fig 2 three analytic
steps are presented: identify units, sort categories, and connect to the text- corroborating /

² The third strategy is “immersion/crystallization style”. Here reading of the text is followed by data
organization and extracts of the most important findings.
legitimating. In this analysis text material is sorted in accordance with predefined categories from theory. In this way certain processes and themes are highlighted, explored and tested. The categories are reconnected to the data in order to identify what corresponds and what differs. Also, reasons for possible divergence are examined. Questions to theory can also be raised. The strategy is further presented in 3.7.5.

The two analytic strategies were combined in a so called double reading. The double reading refers to the interaction between the multilevel interdisciplinary theoretical paradigm as a type of flexible filter, and the analytic process in the three papers. The interaction developed concomitantly with the inductive and deductive approaches, implying that though the analyses were done separately, there was a clear progression. The analysis from Paper I provided a base for the analyses in Papers II and III. Correspondingly, the findings from Paper I defined questions that influenced the choice of theoretical frameworks in Paper II, which in turn defined questions that influenced the choice for Paper III. In the deductive approaches the data was given a voice in terms of influencing how certain parts in and from the theoretical perspectives were emphasized and developed. The black arrows from both the inductive and the deductive analyses back to the theoretical paradigm indicate the generation of questions back to the theory, necessitating additional theoretical components during the process, as well as the preliminary formation of amended theoretical frameworks resulting from the analyses.

3.5 Preparatory work in the field context and recruitment

The preparatory work in the field involved two main aspects: establishing contact with the recruitment sites, and observing routines in the field context.

The preparatory work was crucial in several ways for the execution of the study. First, as the empirical research field, represented by specialized palliative healthcare contexts, was totally new to me, it was important for getting insight into the field's language and way of thinking. In this way identification of relevant issues, problems, and questions was facilitated, which in turn was decisive for the development of the inclusion criteria and the semi-structured interview guide. Furthermore, the preparatory work laid the foundation for the close collaboration with the healthcare staff during the recruitment period. This proved to be crucial for getting access to the participants and for being conscientious about ethical aspects, particularly those related to the inclusion criteria and for gaining informed consent (section 3.1).
3.5.1 Establishing contact with the recruitment sites

The establishment of contact with the recruitment sites included two steps: getting an overview of the cancer units in general, and visiting some of them. In the first step, every leader at the cancer units was requested to send a mail, providing a short description of the unit and of the healthcare professionals there. Since the head nurse at one of the oncology day clinics was an acquaintance from private life, this was a place to start the planning for the second step. She suggested collecting information from a similar clinic situated in a hospital in the other county in the Innland area. This was taken into account. The hospice day clinic, situated close to the same hospital, was also contacted in order to get information from a quite different clinical context.

In one of the scheduled visits to the oncology day clinic, two oncologists participated. They recommended deciding early in the process whether to include patients from the curative or the palliative phase due to the differences in recruitment of participants in these different phases. The clinics were under pressure due to the high and increasing number of patients. Frequently, patients had to receive treatment with others in the same room. How patients handled the cancer disease varied a lot and personality seemed to be more important than age. The leader at the hospice clinic emphasized the clinic’s holistic approach, and that this was important to help people in the completion of their lives.

3.5.2 Observing routines in the field

The observation period lasted for three weeks. It included visiting three contexts during the winter of 2011: one oncology day clinic, one medical ward, and one hospice day clinic. During this period, older people receiving palliative care comprised approximately half of the patients with cancer at the oncology day clinic and the medical ward. The exact number could not be counted at the hospice. The collaboration with the healthcare staff was central in this period as my role as being in the researcher’s role necessitated time to reflect and write down field notes as a part of the process. The researcher’s presence did not seem to interfere too much with the daily routines or the staff’s interactions with the patients. Central for the observation were the ordinary daily routines such as treatment meetings, doctor’s regular visits with patients, nursing care situations, and group activities with patients.

In particular, the conversations with older patients receiving palliative care and healthcare staff were important for the development of the inclusion criteria and the semi-structured interview guide. At the oncology day clinic it was difficult to talk to patients due to confidentiality concerns, as most of the patients were sitting next to others while receiving
palliative care. Some patients were alone in a single or double room, thus conversations with them were feasible. This aspect was a recurring theme when talking to the healthcare professionals, thus emphasizing the difficulties in talking to patients about psychological and existential issues. At the hospice, this was different. Here having a smaller group of patients and rooms suitable for confidential conversations allowed for another type of communication, including attentiveness to existential and psychological issues.

One general impression was the heterogeneity in the group of older patients in relation to symptoms, side effects of treatment, and reactions to the disease. Seeing the positive and comprehensive effects of anesthesia for cancer pain was striking. Some patients totally changed from one day to the next, from a state of being overwhelmed by pain and worn out, to having a reduced anxiety level, better appetite, better sleep, and a renewed need for activities.

An appointment was made with the following healthcare professionals: oncologist, assistant doctor, oncology nurse, hospital priest, head nurse at the radiotherapy unit, head nurse, a doctor in a palliative care team, and all the members in another palliative care team. Here it was emphasized that older people were the largest group of patients in general, thus strengthening the initial impression that older patients receiving palliative care comprised a major and relevant group to study.

3.5.3 The steps in the recruitment process
The recruitment period lasted from November 2011 through June 2012. During the first six weeks only one participant was recruited. One reason was the low number of patients matching the inclusion criteria in the palliative care teams. Most of the patients were either terminal or younger than 70 years old. Consequently, and in line with previous recommendations from the field, recruitment was extended to the oncology day clinics and the medical ward. In addition, the radiotherapy unit was included since it covered the whole geographic region.

The process of getting access to potential participants required a close collaboration with the recruitment sites, especially the head nurses and the leading oncologist/physician. The importance was particularly elucidated in the first period when the level of recruitment was low. Some misunderstandings happened such as inconsistency between the project outline and the inclusion criteria, and the criteria themselves. A patient aged 67 was informed about the study by a head nurse, unfortunately then having to be informed about the age limit subsequently. Such episodes increased the awareness of checking the inclusion criteria for
every participant together with the responsible staff. In this phase five patients withdrew after inclusion, due to a sudden worsening in their health condition. For two of these the interviews were canceled as they were about to start. Under these circumstances it was a great advantage to be a team of two researchers collecting data, allowing for reflection related to unanticipated events.

Basically, the recruitment process involved four steps. These developed as result of the initial recruiting problems and recommendations from the recruitment sites:

1) Contact once a week with the head nurses to check potential participants,
2) If positive, an appointment was made for getting information and perhaps meeting the potential participant at the recruitment site,
3) Receiving information at the recruitment sites, checking it against the inclusion criteria, (The first information with the information letter was given by the head nurse or deputy. If negative, the process ended here. If positive, an appointment for an interview was made by the primary researcher directly with the participant.) and,
4) Collecting the written consent and conducting the interviews.

The four-step recruitment process was particularly important for two reasons. It allowed for the inclusion criteria to be continuously reviewed. A couple of times cognitive functioning was questioned in step 3, implying that the patients were not to be included. The same happened with one patient with serious hearing problems. As for the informed consent, the recruitment process was important for ethical considerations (see section 3.5). Five of the total 21 participants were recruited in a different way due to the distance to the recruitment site. The strategy was initiated by a head nurse:

1) The head nurse contacted the actual patient, informed about the study and gave the information letter,
2) If positive, the head nurse gave the contact information to the primary researcher by phone,
3) The participants were contacted by phone for the interview appointment, and
4) Collecting the written consent and conducting the interviews.

Two differences between these types of recruitment processes were discernible. In the latter strategy, the checking of the inclusion criteria had to be done during the interviews in case of divergences. To stop the interview for such reasons would have been problematic for ethical
reasons in terms of experiencing exclusion after sharing sensitive information. One interview was cancelled right before it was about to start, due to the participant’s abrupt health deterioration. The recruitment site was unaware of this. The second difference was that in the latter strategy the participants were greeted for the first time in the interview situation. This was experienced as a more stressful situation for the primary researcher, and probably also for the participants.

After recruiting half of the participants nine men and two women had been included. According to the recruitment sites the explanation for this imbalance was that men comprised a higher number of patients than women during this period. To increase the proportion of women was seen as the only needed adjustment. The head nurses at each recruitment site were informed about the adjustment.

Finally, none of the participants was recruited from the two palliative care teams and the radiotherapy unit. One of the palliative care teams had initially approached five patients. According to the head nurse, the patients found it too demanding as they were already relating to a large number of professionals. In addition, most of the patients were under 70 years old. At the radiotherapy unit, the seven patients approached did not respond after receiving the information. The head nurse understood this reaction in two ways: the short period of treatment time at the unit, 10-15 minutes, and the low energy levels of the patients. Most of the approached patients at the medical ward refused due to low energy levels. For a few, the study was seen as irrelevant.

In the total sample of 21 participants 19 were recruited from the two oncology day clinics and two from the medical ward with eight cancer beds. The participants were recruited from palliative care at the second level of the public healthcare system (see 2.1). Thus, the main focus was on their experiences while receiving palliative care at this level. However, as more than half had received palliative care from the first and third levels, the experiences from these levels were not without influence.

3.6 Data collection
This data collection process section includes both method and process information in the following areas: inclusion criteria, semi-structured interview guide, and information on conducting the interviews.
3.6.1 Inclusion criteria

The inclusion criteria were the following: older people age 70+; including all cancer types, diagnosed with cancer in the palliative phase, being informed and having an understanding of the diagnosis, recruited from two oncology day clinics, a radiotherapy unit, a medical ward, and two palliative care teams, considered by specialized health care regarding cognitive and emotional status as suitable for interviewing, living in their home, and, not having reached the terminal phase.

The development of the inclusion criteria was informed by different factors. One was the insight gained from the preparatory work in the field. Another was the response from central healthcare professionals when sharing the study plans at meetings and conferences. The inclusion of patients with longer life expectancy, receiving palliative care from cancer units was suggested and included. A staff assessment of cognitive and emotional functioning was also included. No independent instruments were used for the identification of psychological function or dysfunction. This was consistent with the hermeneutical methodological paradigm, focusing exclusively on interpretations of the text material and not on the participants' psychological health as such.

The reason for including patients with all cancer types was that the research question was seen as relevant for all cancer patients. In the project outline, the original age was 65+ years. This was changed to 70 years. The main reason was to exclude patients that were in a period of handling changes and restrictions in their job situation due to health constraints. By selecting the age of 70, most of the patients would be retired. If their last job period had been problematic because of the cancer illness, it still belonged to the past.

3.6.2 Semi-structured interview guide

The semi-structured guide is presented in Appendix 4. The reason for selecting this type of interview was that it was in accordance with the objective of exploring specific experiences. As described by Kvale and Brinkman (2009) the interview is closely related to a normal conversation in daily life. The main difference is that is has a purpose, involving a certain approach and technique. Thus, the guide combined open questions, specific questions, and themes, implying that the participants could share narratives about their experiences and give shorter comments on specific issues.

The guide was structured for covering participants' reflections retrospectively and prospectively concerning four life periods: life before the cancer illness, time of cancer diagnosis, life at present, and future aspects. The questions were presented through openly
stated how- and what-questions. Under each time period there were sub-questions, covering a broad range of issues for deeper exploration. In this connection, the guide functioned as a checklist. Two conceptual frameworks guided these questions and issues. The first was the holistic understanding of palliative care, comprising physical, psychosocial, and spiritual domains (World Health Organization, 2014 a) (1.3.2). This was framed as the “biopsychosocioexistential” framework here. This framework has been applied both in palliative care research (Whitford, Olver, & Petersson, 2008) and in mental health fields such as psychiatry (Josephson & Peteet, 2004). From this framework the broad range of issues in the participants’ daily living were included. The specific issues covered were: comorbidity, experiences with palliative care, bodily reactions and changes, relational aspects, core experiences in life, continuation/consistency/chaos, and, existential meaning-making.

The second framework was the broad understanding of spirituality from the EAPC definition (Nolan et al., 2011), implying that different questions were asked in relation to existential meaning-making. The following question was asked in relation to the time periods present life situation, life before the illness, and life after cancer diagnosis: What is most important in your life/gives meaning/strength/comfort…? The other questions were: What do you associate with the concepts existential and spiritual? How would you describe your basic life attitude? What are your reflections about the future and death? Do you talk to anyone about these matters? Do you consider it as important to talk to the healthcare staff about these matters?

One change was made in the interview guide. After the first interview, the following question was added: “What do you associate with existential and spiritual issues?” The main reason for adding this question was to explore how the concepts were perceived. The concepts were used in the patient information letter (see Appendix 1). This might have contributed to reflections beforehand that were relevant for the study.

3.6.3 Information on conducting the interviews

The circumstances for conducting the interviews varied as the participants decided the choice of setting: fourteen at home, six in the hospital, and one during a temporary stay in a nursing home. Two of the participants were interviewed while receiving chemotherapy treatment. For the five interviewed at home, a husband or wife was present part of the time or during the whole interview. The decision to include them was made by the participants, and for this reason their contributions were included in the transcripts. They gave different types of
additional information, such as supporting remarks, corrections, new information, and nuances.

To confirm that the appointment still was agreed upon, the participants were contacted by phone a couple of days before the interviews. Directly before each interview started the written consent form (see Appendix 1) was signed by the participant. If done previously, the consent was checked and verbally confirmed. The interviews lasted from 20 minutes to 1 ½ hours. In most cases, they lasted around 1 hour.

Two researchers took part in the interview process. The primary researcher was responsible for the recruitment process and for conducting the interviews. When conducting the interviews, the Mayo’s guidelines (Kvale & Brinkmann, 2009, p. 65) for qualitative interviews were kept in mind: undivided attention, listening, avoid giving advice, summarize understandings in order to check with the participant, and the duty of confidentiality. Listening carefully and letting the participants’ reflections lead the way through the semi-structured guide were paramount. The order of the four time dimensions depended on the participants’ way of responding. In a few cases, life before the cancer illness was the first item to be reflected upon. Some participants started talking about the present situation. A few reported that their relation to the future and death were too difficult to talk about. The secondary researcher was a skilled interviewer. She took field notes during the interviews. During the interviews, the secondary researcher also made sure that the audio recorder was on, considered the participant’s health situation, and commented if something was overlooked in relation to the interview guide. After the interviews she gave her response and reflected on the interview. The second researcher was unable to participate in three interviews. In these interviews the focus of attention was entirely on the interaction with the participant. The field notes were written down right after the interview by the primary researcher. These field notes, naturally, were not as detailed and thick as when written down during the interview by the second researcher.

3.7 Data analyses

In this section the data analyses are presented. The transcription procedure is seen as a part of the data analysis, thus it is included here. The section is structured into the following parts: transcription procedure, field notes and memos, qualitative data analysis programme, data-driven analysis, and theory-driven analysis.
3.7.1 Transcription procedure
Independent of transcription procedure, an exact reproduction of the verbal expressions is impossible (Malterud, 2011). The aim in this study was to reproduce the content as precisely as possible by staying as close as possible to the recorded interviews. This involved marking interruptions, breaks, hesitancy, bodily movements, and emotional expressions such as laughing and crying. Several participants used dialects where some words could differ from those of standard Norwegian. These were transcribed into standard Norwegian to simplify the reading for the members of the research-group, one of whom was Swedish. This was problematic as the original meanings where changed and thereby lost. To counteract this pitfall the unusual words were underlined and explained in the text. The interviews were transcribed by the primary researcher. After each transcription the primary researcher listened to the tape recorded interview while reading through the transcript, checking for mistakes and errors.

3.7.2 Field notes and memos
Field notes and memos from the fieldwork- and recruitment periods comprised reflections on the research process, particularly concerning initial reflections from the interviews, contextual factors, and methodological and ethical considerations and challenges. This material was not analyzed in the same way as the transcripts due to the main objective of the study. However, from a hermeneutical perspective the reflections were seen as embedded in the “hermeneutical cycle” and the “hermeneutical situation”, thus deepening the understanding of older people’s experiences by taking the particular context, period in history, and the “horizon” into consideration. For instance, contextual conditions at the recruitment sites such as heavy workload for the health professionals affected the recruitment process and the selection of the participants. Another example is the place where the interviews were conducted, whether it was at home or at the hospital. In the first case, the interviewer was more like a guest, meeting the participant on his/her premises. In the second case, the interviews were affected by the routines and work at the recruitment sites. At home the participants’ situation in daily living was accessible in a very present way in comparison to hospital contexts.

3.7.3 Qualitative data analysis programme
The qualitative data analysis programme QSR NVivo (Version 10) was utilized. On a general level the data coding of the text material became important for the systematization of data for both the inductive and deductive approaches. Meaning units that belonged together were
stored in a container called a node. When the node was opened in the program, all the references were available in one place. This made it easy to identify citations for the analysis. The programme had certain functions such as word frequency query, classification system and colouring. The query provided an overview of the most dominant themes in the material. However, this function was not essential for this study. The classification system gave an overview of demographic information at the time of the interviews, being useful when making the demographic table. The colour function marked the quantity of each node within the interview text. This allowed for three possibilities: to easily see patterns in relation to dominating and less dominating themes, checking if a passage of the text had been omitted from the coding, and checking for inter-rater consistency tracking by the research group members.

### 3.7.4 Data-driven analysis process

In Paper I the interview material was analysed with the strategy “systematic text-condensation”. The four steps developed by Malterud (2011, 2012) are applied below.

The aim in the first step was getting a bird’s eye view of the material as a whole, also called intuitive reading. Themes that appeared in the material were written down on a large piece of paper in an unstructured way. A summary from the initial reading was written down.

In the second step, the qualitative data analysis programme, QSR NVivo (Version 10) was utilized for identifying and organizing the data. The parts of the material that elucidated the research questions were sorted out into meaning units and coded. The themes from the first step were included in the coding. The coding represented decontextualization because parts of the text were removed from the primary context. During this step, the transcripts were also coded on paper. The nodes from the computer-based coding were identified and coloured and reflections were written down. This coding was experienced as important for the sake of getting the material ‘under the skin’, thus reinforcing the reflections and questions identified in the analytic process.

In the third step the main question concerned the kind of answers the text was giving to the research questions. The coding was condensed into meaning units, followed by sorting them into a few subgroups. For each subgroup meaningful descriptions of the content were formulated, preferably quotes from the informants and concepts from the meaningful units. The transcripts were also analysed differently in a diagram containing three predefined categories: relationships, problems, and resources. The subgroup existential meaning-making
was added to each of the categories in order to identify patterns and variations. Citations and descriptions from each participant were placed under the categories. In this way the categories were checked against the data material.

In the fourth and last step the subgroups and categories were compared, merged and recontextualized, considering whether they were consistent with the context from which they were originally taken. Attention was given to the parts that contradicted the conclusions, and also to informants who differed from patterns in the main findings. Thus, critical and necessary questions as to the conclusions could be raised. Finally, the conclusions were evaluated in light of relevant research and theory. This led to the findings in Paper I, describing the illness experiences of the participants from their vantage point.

3.7.5 Theory-driven analysis process
In the theory-driven analysis termed template-analysis style (Malterud, 2011), theory and conceptual frameworks were applied as lenses for the interpretation of the data. According to Malterud this strategy involves a risk of reproducing knowledge that is well known (2011, pp. 95-96). On the other hand there is also the chance to develop new descriptions.

In Paper II, the expressed illness experiences were more clearly defined through the lenses of an operationalized existential meaning-making framework. This included four concerns: a belief frame, value in and meaning in life, life attitude, and the relation to future and death. The framework was added to the life-span model ‘selective optimization with compensation’ (SOC) (M. M. Baltes & Carstensen, 1996; Baltes P.B. & M.M., 1990; P. B. Baltes et al., 2006). The application of the SOC model was used as an analytic tool for analysis of all the interviews. The analysis here was limited to the existential framework and the SOC strategies. The text material was analyzed in two steps. First, the material was reviewed line-by-line for each of the three strategies in SOC for identifying units and sorting in categories. This led to a general overview of type of behaviors, including patterns in the employment of the SOC strategies. Second, the operationalized existential meaning-making framework was explored within each strategy, identifying patterns, variations, and themes, leading to the identification and exploration of the super-ordinate observation and the sub-observations.

In Paper III the analysis of the illness experiences was narrowed through the lens of the cultural framework originally developed by Kleinman (1980; 1978), and further elaborated and applied to palliative care in a Scandinavian context by DeMarinis (1998, 2003). In this way cultural contexts were included in the analysis. Reframing the illness experiences was in focus here. A smaller group of the participants were selected as case illustrations, representing
the range of belief frames identified in the total sample. Also in this paper the text material was analyzed in two steps. First, the five-dimension cultural framework was applied broadly to each case for an overview of units, categories and patterns. Second, the interaction of information among the dimensions were analyzed, with special attention to the function of the existential domain. The comprehensive analysis was extracted and summarized as case illustrations.
4 Results

In this chapter the three papers in the study are shortly presented first. Then there is a summary of the results and a figure (Fig 3), illustrating the main finding and sub-findings.

4.1 Paper I

Objective and background: The objective of Paper I was to describe how the participants experienced daily living while receiving palliative care in specialized healthcare contexts. Despite that this group of elderly persons represented an increasing proportion of patients in these clinical contexts, the amount of research for this age group has been quite limited. Studies with patients ranging from age 20 and upwards, with both shorter and longer life expectancy show that patients with incurable cancer seem to have in common experiences of being connected to life and different types of oscillation movements. The content of the movements are described as struggles in relation to the existential, physical, psychological and social domains. Also, increased attention has been given to resilience in studies on people living with chronic illnesses.

Method: Twenty-one participants, 12 men and 9 women aged 70-88, were interviewed with a semi-structured guide. They were recruited from two somatic hospitals in southeastern Norway. The data were analyzed with a phenomenological descriptive approach called systematic text-condensation. The “biopsychosocioexistential” framework was applied as the main perspective on the data material.

Results: Existential meaning-making and resilience appeared to be the overarching processes for these older people formulated as the strong link to life in the present. The processes interacted in terms of: acknowledging the need for close relationships, maintaining activities of a normal daily life, providing space for existential meaning-making, and naming and handling decline and loss. In addition, they experienced that specialized healthcare contexts strengthened the link to life by prioritizing and providing person-centered palliative care. A figure with the findings is presented in Appendix 6.

Conclusion: Insights into the processes of existential meaning-making and resilience were seen as useful in order to increase the understanding of how older people with incurable cancer adapt to adversities, and how their responses may help to protect them from some of the difficulties in aging. Healthcare professionals can make use of this information in treatment planning and for the identification of psychosocial and sociocultural resources to support older people and to strengthen the person’s own life resources.
4.2 Paper II

**Objective and background:** The aim of Paper II was to understand how the participants experienced the existential meaning-making function in daily living from a life-span perspective. The overall finding from Paper I concerning the processes of existential meaning-making and resilience were taken a step further, applying theoretical analysis on the same data material. Resilience has been used in different ways in gerontology, palliative care, and life-span developmental psychology. From gerontology research the concept ‘resilience repertoire’ was selected due to a holistic understanding and a growth dimension. In life-span developmental psychology resilience has been explored through the model ‘selective optimization with compensation’ (SOC), understood as restoration and maintenance of behavioral functioning. As seen in several studies on chronic illnesses, the SOC model was found to be a basic framework for investigating how people adapt and manage difficulties. It has also been applied as an analytical tool in some qualitative studies. Based on the phenomenological analysis in Paper I the existential meaning-making experiences were operationalized into a framework with four concerns; a belief frame, value in and meaning in life, life attitude, and relation to future and death. This framework was added to the SOC model.

**Method:** Theoretical analysis of the interview material, involved two steps. In the first step the interviews were reviewed line-by-line for each of the strategies in SOC. In the second step the existential meaning-making framework was added to the SOC model. Through this functional approach the impact of existential meaning-making on the SOC strategies was explored. A figure illustrating the method and findings is presented in Appendix 7.

**Results:** The participants experienced the existential meaning-making function on two levels. On an overall interpretive level it was an important component for understanding and coordinating the adaptive strategies of SOC for reaching most important goals in daily living. The existential framework provided for a comprehensive understanding of resilience, allowing for both restoration and growth dimensions to be identified. The second level was a daily living strategy level, in that existential meaning-making was involved in a complex interaction with behavioral resources and resilience for continuation of life goals and more realistic goal-adjustments. Though the adjustments made by many involved grappling with painful issues, and struggling to make changes, their meaning making processes allowed for such. A few, however, experienced existential meaning-making dysfunction, whereby their meaning making processes lacked resources or could not accommodate adjustments. If the participants’ expressions included statements about psychological matters this was analyzed.
in accordance with the analytic strategy. In this connection psychological dysfunction was present to a limited degree in some of the cases.

**Conclusion:** The findings supported and extended the findings in Paper I that existential meaning-making and resilience appeared to be the overarching and interrelated functions for these older people. The modified SOC model might permit older people to have an active voice in how meaning is made and shared throughout the adaptation process as incurably sick. Combining the SOC model and the existential meaning-making framework with the resulting more comprehensive approach to resilience might provide a fruitful next step in both theoretical- and clinical development for palliative care populations.

### 4.3 Paper III

**Objective and background:** The objective in Paper III was to understand how the participants reframed their illness experiences in light of existential meaning-making adjustments. The need for an ethnic majority population focus on the reframing of existential meaning-making experiences emerged from the analysis in Papers I and II, finding that the patterns and content of these experiences were very different, pointing to different cultural processes with different orientations to clinical reality. Research exploring socio-cultural understandings of illness experiences as well as an elderly population focus has been emphasized in palliative care and WHO. Little attention has been paid to these aspects in palliative care in Norway. Research in the mental healthcare field in Norway has identified the clinical need for a culture-focused perspective for all patients. Existential meaning-making is understood as fundamental for how cultural interpretations of health and illness are perceived and practiced.

**Method:** Four case illustrations from the sample of 21 participants were selected for the cultural – and existential meaning-making analysis, representing the variation in existential meaning-making expressions identified in Paper I: atheistic/humanistic; religious; and spiritual. Kleinman’s cultural framework from medical anthropology, further elaborated and applied to palliative care contexts in Scandinavia by DeMarinis, was adopted for the analysis. The framework included the following five dimensions: the biological-physical, the psychological, the social, the ecological, and the existential dimension. The interviews were analyzed similarly to the strategy in Paper II. First, the adopted cultural framework was applied broadly to each case. Second, special attention was given to the function of the
existential dimension in relation to the other dimensions. A figure with the cultural framework and a table illustrating the findings are presented in Appendix 8 and 9, respectively.

**Results:** The main finding was that the four case illustrations reflected heterogeneous cultural processes while living with incurable cancer. Independent of the cultural variation, the framing-reframing process appeared to contribute positively to constructions of illness and health, the relation to the surroundings, and the adjustments made in daily living. Thus, the existential dimension served to connect and in many ways coordinate modifications in the other dimensions in relation to both approaches to and experiences of illness, disease, and health in the person’s local world.

**Conclusions:** Information gained through cultural- and existential meaning-making analyses at the national-, local context,- and individual levels contributed to a more nuanced understanding of older people’s varied interpretations and modifications of living with incurable cancer in this cultural context. The results point to the need for including these types of analyses and its resulting information in the clinical process for understanding the patient’s framework of interpretation, and for identifying treatment planning resources.

### 4.4 Main finding and sub-findings

The answers to the research question in the study are illustrated in Fig.3 below. The main finding was that the participants expressed a strong link to life in the present. This was accomplished by the illness reframing process facilitated in large part by existential meaning-making experiences. Three sub-findings in the illness reframing process were identified as central for the psychological functions of the existential meaning-making experiences in daily living. The first sub-finding (Paper I) was that existential meaning-making interacted with resilience in terms of: acknowledging the need for close relationships, maintaining a normal everyday life, providing space for existential meaning-making, naming and handling decline and loss. The second sub-finding (Paper II) was that existential meaning-making was a component in the adaptation process of reaching the most important life goals. This was identified on two levels: a super-ordinate level for coordinating and interpreting the SOC strategies, and a strategy level for interacting with resources and resilience. The third sub-finding (Paper III) was that existential meaning-making appeared to facilitate positive cultural processes, exemplified in the case illustrations, in relation to facilitated new or altered constructions of illness and health, improved relating to the surroundings, and assisted in making adjustments in daily living.
**Main finding:** Older people with incurable cancer: The strong link to life in the present accomplished by the illness reframing process of the existential meaning-making experiences, identified as central for three domains in daily living:

**Sub-finding 1:** Interacting with resilience in terms of:
- Acknowledging the need for close relationships, maintaining a normal everyday life, providing space for existential meaning-making, naming and handling decline and loss

**Sub-finding 2:** A component in the adaptation process of reaching the most important goals:
- A super-ordinate level for coordinating and interpreting the SOC strategies, and a strategy level for interacting with resources and resilience

**Sub-finding 3:** Facilitating positive cultural processes in a smaller group of the sample in relation to:
- New or altered constructions of illness and health, improved relating to the surroundings, and adjustments made in daily living
5 Discussion

The chapter has two main sections: a discussion of the results and a critical review of the study.

5.1 Discussion of the results

This section is structured in line with the main finding and sub-findings illustrated in Fig 3: the illness reframing process of existential meaning-making experiences, existential meaning-making interacting with resilience, existential meaning-making as a component in the adaptation process of reaching the most important goals, and existential meaning-making as facilitating positive cultural processes. The findings are analysed in relation to the research review presented in 2.3.

5.1.1 The illness reframing process of existential meaning-making experiences

The approach to psychological function and dysfunction of the existential meaning-making experiences in the study was described as the pragmatic functional approach (2.2.1). The focus was on the roles and purposes these experiences served in the daily living of the participants. On this basis the illness reframing process of existential meaning-making experiences was seen as the overall process and theme for the participants, central for the understanding of their illness experiences.

As described in 1.3.1 the conceptual understanding of illness experience was derived from the prominent medical anthropologist Kleinman (1980, 1992, 2013; 1991), making a distinction between disease and illness. Illness represented the participants’ verbal responses to the incurable cancer disease, including physical reactions, psychosocial experiences and meaning ascribed to the illness. The holistic perspective on the responses was in line with the WHO definition of palliative care (2014 a) and the “biopsychosocioexistential” framework applied in the study. The term experience was understood as a holistic, individual, relational, continuous, and contextually-anchored process. When illness and experience were combined it allowed for the identification of the three sub-findings illustrated in Fig 3.

The understanding of reframing was derived from the psychotherapeutic tradition (Mattila, 2001). Here the focus is on helping people to change the meaning of a particular event. This involves changes in the categorization, concepts, and metaphors that are attributed to the situation (Mattila, 2001). As clarified in Paper III, the definition was related to the participants’ illness experiences from their vantage points. The illness reframing process was
seen as an important part of their own interpretation process for dealing with the difficulties. Park (2005, 2010) understands the concept meaning-making in a similar way, referring to it as “the process of coming to see the situation in a different way and reviewing and reforming one’s beliefs and goals in order to regain consistency among them” (2005, p. 299). This approach to meaning provides insight into the complex relation between the global meaning and meaning making process under difficult life circumstances. From the hierarchical model underlying the SoMe (2009, 2010, 2011), Schnell also understands the experience of meaning in life as involving complex processes. To my knowledge the SoMe has not been tested on patients with chronic illnesses, implying that little is known about what happens to the allocation of the 26 sources of meaning when dealing with health constraints and loss. Interestingly, generativity was identified as the strongest predictor for experiencing meaning in life. This was also a central finding in this study.

Pargament’s understanding of the terms “religious reframing” (1997, p. 221) and “spiritual reframing” (2007, p. 272) is quite similar to the understanding of reframing in the study. However, to connect reframing to the terms religious and spiritual was seen as problematic. For Pargament, reframing as a complex cognitive function is linked to a particular understanding of religious and spiritual. In this way reframing is tied to a restricted meaning, thus increasing the risk of excluding other relevant domains and aspects. For this reason it was not considered as appropriate in the study.

The sentence “the strong link to life in the present” was the main metaphor for the illness reframing process. I first discovered the metaphor in a short poem by the Norwegian poet Kolbein Falkeid (Bakkemoen, 2012). In my translation it goes: “The older one gets, the stronger link to life one gets”. I read this during the first analytic step right after the data collection was completed, finding that it summarized my initial impressions of the participants and their reflections. During the analysis phases in each of the three papers, this impression was increasingly and repeatedly confirmed. As described in Paper 1, experiences of being linked to life seemed to be a common experience in patients with incurable cancer. Interestingly, similar metaphors have been used in palliative care research in Scandinavia: “links to life” (Sand et al., 2009); “latching onto life a bit longer” (Sæteren et al., 2010); and, “connections to life” (K. La Cour et al., 2005).

A metaphor can be understood as both a process and a product (2.2.3). Both understandings were relevant for the participants. As a process the metaphor was a headline for the main finding and sub-findings, illustrated in Fig 2. Viewed from a functional approach
to existential meaning-making, the metaphor served to clarify the processes in the sub-
findings. As a product the metaphor illustrated specific experiences of seeing things in a new 
light. In particular, this was identified in the case illustrations in Paper III. For instance, Liv 
experienced acceptance of the colostomy, involving a clear reframing of how life could be 
lived despite the incurable cancer. Hans reframed his life story after having received 
symptom-reducing effects of radiotherapy treatment.

Insight into the complex cognitive functions of concepts and categorizations was important 
for understanding the illness reframing process (2.4). Through these functions the world was 
simplified, filtered, and personalized, in the sense that the information stored in the memory 
of each participant was recognized. In this way, they got access to their life history. As noted 
in Paper I, a common feature for all the participants was that previous life experiences were 
seen as helpful for handling current adversities, although it was difficult to describe in detail. 
The concept ‘resilience repertoire’ from gerontology (P. G. Clark et al., 2011) included this 
aspect. By organizing the skills and resources in relation to themes and values from one’s life 
story, the very personal way of dealing with the incurable cancer became realized. A similar 
pattern was also found in studies on younger patients with cancer (McTiernan & O’Connell, 
2014; Sand et al., 2009). In the study on storytelling (Synnes, 2012) of participants aged 43- 
95 this was explored in depth. The narrative identity identified in the stories was 
“characterized by a striving for a connection or a direction” (p. 306). The connection was 
understood as a search for ways to grasp a larger part of one’s life. At times this did not 
succeed in the sense that the narrative identity either collapsed or was put under pressure. In 
many stories this type of connection was seen as a response to the incurable cancer. In most 
stories the cancer illness played a minor role. Here the narrator “constituted themselves as 
something more than a seriously ill person” (p. 306).

Hence, the illness reframing process of existential meaning-making experiences was 
multifaceted and diverse. The aspect of complexity in the age group of older people is well 
known in research (Allen et al., 2011). Approaching the phenomena with the multilevel 
interdisciplinary perspective facilitated this type of insight. Also, it allowed for identifying the 
ilness reframing process as essential for the participants when focusing on daily living. The 
‘multifaceted and diverse aspect’ and the ‘daily living aspect’ referred to here were central for 
understanding the interrelatedness between existential meaning-making and resilience for the 
participants. These two aspects are analyzed further in this chapter.
5.1.2 Existential meaning-making: Interacting with resilience

As illustrated in Fig. 3, the results in Paper I showed that resilience and existential meaning-making were interrelated concepts and processes for the participants in terms of: acknowledging the need for close relationships, maintaining activities of a normal daily life, providing space for existential meaning-making, and naming and handling decline and loss. The multifaceted and diverse aspect refers to the complexity and variability in how the two processes were interrelated in the group of older people in the sample. In Paper I, this was mainly recognized through the analysis of the four subthemes referred to above. According to the structure of this presentation, the subthemes are placed under the ‘daily living aspect’ and presented below.

The application of the conceptual framework “resilience repertoire” (P. G. Clark et al., 2011) from gerontology provided insight into the multifaceted and diverse pattern. An activation of the “resilience repertoire” involved an interaction between the participant and context over time, leading to a multitude of ways of using the skills and resources. Furthermore, factors such as chronic illness with the adjoining problems, experiences from life history, and existential meaning-making influenced the “repertoire” and contributed to this pattern. Essential in this aspect was that existential meaning-making experiences served both as an overarching process and as a subtheme, representing through very different expressions two concerns: the centrality of belief frames and the core of what is most meaningful and valuable in life. As described in Paper II, two more concerns were identified in the analysis and added to the existential meaning-making framework: life attitude, and relation to future and death. The interrelatedness between the two processes has been addressed in a study on older people in a hospice concept (Nakashima & Canda, 2005), thus recommending a holistic and comprehensive understanding of resilience. This was taken into account in Paper II, see 5.1.3.

Palliative care research on reframing has given insight into the multifaceted and diverse pattern. Here reframing has been identified as closely related to: coping with uncertainty (Bailey et al., 2007; King et al., 2015; Mishel, 1990), meaning-constructions (Lethborg C. et al., 2006), hope (Duggleby et al., 2012; Salander et al., 1996; Sze et al., 2006), and storytelling (Synnes, 2012). The aspect of uncertainty has been reported in several studies on patients’ experiences. In Paper I, this was presented as experiences of oscillation movement in relation to all the domains in the “biopsychosocioexistential” framework (Andersson, Hallberg, & Edberg, 2008; Benzein et al., 2001; Lindqvist, Widmark, & Rasmussen, 2006; Maher & De Vries, 2011; McTiernan & O’Connell, 2014; Sand et al., 2009; Sæteren et al., 2012; Sæteren et al., 2012).
In a systematic review of the experiences of older people with incurable cancer (Hughes et al., 2009) the aspect of uncertainty was even enhanced, formulated as living in a “profound state of ambiguity” (p. 1151). The theory of uncertainty in illness (Mishel, 1990) focuses on how uncertainty is dealt with by cognitively processing illness experiences, structuring them into meaning constructs. When accepting the basic human condition of uncertainty in life this might open up for a variety of possibilities and ways of adapting to the difficulties. The finding that the participants’ ways of experiencing and dealing with the difficulties as incurably sick of cancer were manifold and diverse were central in all of the three papers. When exploring the existential meaning-making function in depth, this was accentuated.

The daily living aspect was linked to the four subthemes in Paper I. In addition, the application of the SOC model in Paper II and the adopted Kleinman framework in Paper III were central for understanding the pattern. This is presented in 5.1.3 and 5.1.4. When comparing with other studies in palliative care that included younger age groups, the subthemes were in agreement with findings around themes focusing on living (Benzein et al., 2001; Maher & DeVries, 2011; McTiernan & O’Connell, 2014; Sand et al., 2009; Synnes, 2012; Sætheren et al., 2010). Thus, the old participants did not differ from younger age groups in their experiences of being linked to life.

To acknowledge the need for close relationships was the most dominant theme in the data material. This was verified through the word frequency query in the qualitative data analysis program NVivo. As the Demographic data in Appendix 5 shows, the social factor was very important. Almost two-thirds rated this theme as the most valuable and important aspect in their life, thus clearly showing the interrelatedness between existential meaning-making and resilience. The inter-generational perspective was a prominent factor. In addition, the contact with healthcare professionals in palliative care in specialized healthcare contexts was central in several ways. In a meta-study on spirituality in palliative care the interrelatedness between close relationships and spirituality was addressed (Edwards et al., 2010). Correspondingly, identifying both existential issues and close relationships when exploring patients’ experiences was seen in some studies in palliative care (McTiernan & O’Connell, 2014; Sand et al., 2009; Sætheren, 2006).

To maintain activities of normal daily life in terms of functioning at home was essential for all the participants. For some it was even the most important part in life. Activities in normal daily life included spending time with close relationships and involvement in certain meaning-giving activities. In this respect, continuity of activities before the cancer disease
was a recurring theme, exemplified in housework, physical activity, and hobbies. This also included maintaining the same framework in relation to existential meaning-making. A similar finding was addressed in an Irish study (McTiernan & O’Connell, 2014). The close connection between engagement in activities in daily living and meaning has been thoroughly explored in studies from Denmark by La Cour and colleagues (2012; 2009; 2005).

The subtheme of providing space for existential meaning-making included a multitude of experiences, ranging from health-related constraints to core experiences from life history. This indicates that the way the existential meaning-making framework was operationalized here was one out of several possibilities. As referred to above, the theme of close relationships was at the core of the existential meaning-making experiences. The need to include a broad variety of existential meaning-making expressions as exemplified by the three types identified in this study: atheistic/humanistic, religious, and spiritual, has been supported by clinical research in Scandinavia (Ahmadi, 2006; DeMarinis, 2008; P. la Cour & Hvidt, 2010). Engagement in activities reaching outside oneself and giving help to others, termed self-transcendent behavior, was a part of this theme. This is further analyzed in 5.1.3.

The subtheme of naming and handling decline and loss emerged from the comprehensive narratives concerning the participants’ responses to the disease trajectory. The verbs ‘name’ and ‘handle’ referred to their own expressions and not to psychologically-based assessments. Insights into the domains of oscillation movements and of uncertainty in chronic illness were seen as central for understanding this theme. On the basis of the “biopsychosocioexistential” framework and perspective the participants’ struggles were identified as involving every aspect and domain of life. Relation to the future and death, which was one of the concerns in the existential meaning-making framework, was the most difficult theme. This was also identified in relation to the SOC model regarding the dynamic between loss-based selection and compensation (5.1.3). Hence, the variation in the participants’ responses seems to indicate different degrees of resilience in the participants (Hardy et al., 2002). However, this aspect was not further examined.

5.1.3 Existential meaning-making: A component in the adaptation process of reaching the most important goals

In Paper II the interrelatedness between existential meaning-making and resilience was taken a step further through the modified application of the SOC model from life-span developmental psychology. In this way, deeper insight into the ‘multifaceted and diverse aspect’ and the ‘daily living aspect’ was attained. The essence in SOC application to daily
living is that adaptiveness to challenges and demands is enhanced when people set clear goals (selection), invest means and resources for reaching them (optimization), and act persistently in the midst of constraints (compensation) (Freund & Baltes, 2002). Research has shown that the importance of the SOC strategies increases by aging (P. B. Baltes et al., 2006; Thygesen et al., 2009). The research review (2.3.4) concluded that the SOC model was found to be a useful framework for investigating how people adapt and manage certain difficulties when living with chronic illnesses (Alonso et al., 2013; Donnellan et al., 2012; Donnellan & O’Neill, 2014; Janke et al., 2011; Rose et al., 2008; Wilhite et al., 2004). However, existential meaning-making was not elaborated in this research.

The main finding in the current study was that the existential meaning-making function, for the majority of the participants, was central for the adaptation process of reaching the most important goals in daily living. This included two levels; the superordinate level and the strategy level. Among the participants, only a few shared experiences of existential meaning-making dysfunction, due to lack of resources or an inability to make an existential adjustment for reframing. This was seen on both levels. This data was not further pursued in these papers.

On the superordinate level, the existential meaning-making function was identified as a component for interpreting and coordinating the adaptive strategies of SOC. In this connection the important role of culture and cultural activities for the participants, in agreement with the bio-cultural framework of the SOC model (P. B. Baltes et al., 2006), assisted the function of existential meaning-making and thereby the adaptive strategies. The role of culture was incorporated into Paper III, see 5.1.4 below. There were two main patterns found. First, the four concerns in the existential framework were related to the understanding of resilience as a comprehensive process, incorporating both restoration from SOC and the more holistic growth dimension from “resilience repertoire” (P. G. Clark et al., 2011). Second, there was great variety as to the content and the function of the existential frameworks, as well as to dynamic processes underway for each of the participants. More specifically, the existential framework information appeared to provide a comprehensive means for both tracking and understanding the on-going adjustments made in the meaning narrative in relation to resilience, including both new areas of growth for the adaption process as incurably sick, and for the realization of loss and decline.

On the strategy level, the existential meaning-making function, including the level of function, was involved in each of the strategies in the SOC model. The combination of alternation between the strategies together with the diversity in the content of the existential framework and the comprehensive process of resilience contributed to the variation. In each
of the strategies, the importance of the daily living aspect was highlighted. In some studies on chronic illness, variability in the SOC strategies has been identified, seeming to be central for minimizing difficulties with disability and weakness in daily living (Gignac, Cott, & Badley, 2002; Rush K.L., Watts W.E., & J., 2011a; Rush et al., 2011b).

Three characteristics related to each of the strategies were identified for the study’s participants. First, continuation of goals from life previous to the incurable cancer disease was inherent in the selection strategy. All four concerns in the existential meaning-making framework were involved in this type, perhaps indicating that existential meaning-making was essential in the process of enabling continuity across the life-span. In gerontology research increased attention is paid to the influence of previous life experiences for handling current adversities (P. B. Baltes et al., 2006; P. G. Clark et al., 2011). This aspect is analyzed in 5.1.1.

Second, self-transcendent behavior and the supportive and personal side of a belief frame were identified as central in relation to optimization. Self-transcendent behavior involved reaching outside oneself for the benefit of others particularly in the domains of close relationships and meaningful activities. It was identified in relation to all four concerns in the existential meaning-making framework. In Erikson’s life cycle theory (1997) generativity is the preferred term, representing the major theme from the adulthood period and into old age. In the measurement SoMe, generativity is identified as the strongest predictor of meaningfulness (Schnell, 2011). For the participants the supportive and personal side of a belief frame strengthened the optimization strategy along with experiencing great difficulties. Thus, the interrelatedness to resilience was identified.

Third, regarding the dynamic between loss-based selection and compensation the existential framework facilitated a reframing of goals for the benefit of more realistic goal adjustments. The reframing included both reframing of loss- and growth-related experiences. This corresponded with resilience as accounted for in the SOC model, and resilience identified in relation to growth and the framework “resilience repertoire”. Insight in reframing, uncertainty in illness, and the oscillation movement were seen as important for understanding the complex dynamic between loss-based selection and compensation (5.1.3).

5.1.4 Existential meaning-making: Facilitating positive cultural processes
As outlined in 5.1.2 and 5.1.3 the multifaceted- and diverse aspects were central for understanding the interrelatedness between existential meaning-making experiences and resilience. This pointed to different cultural processes in the participants and their different
orientations to clinical reality. For this reason, the main focus in Paper III was on cultural processes of illness and health.

Main theorists in life-span developmental psychology such as Baltes and colleagues and Erikson (2006; 1997) have been critical to tendencies in western culture concerning the period of old age. A bio-cultural perspective on the life-span (P. B. Baltes et al., 2006), where culture serves the important function of compensating for loss and decline by drawing on the aging itself has had little attention. There is a tendency to allocate most of the resources and efforts to younger age groups. Another tendency has been addressed by Erikson (1997), pointing to the lack of concepts and constructs that capture a sustainable ideal of the whole of life. In the chapter including the ninth stage of development, Joanne Erikson formulates the problematic aspects as clear detriments: “this century’s response to aged individuals is often derision, word of contempt, and even revulsion” (p. 116). Hence, there is a need in western culture to integrate the biocultural model from SOC theory on the life-span for including the unavoidable and increasing biological weakening in aging as a normal process in life. The findings in Paper II concerning the optimization strategy and plasticity might be an illustration of another central point in the SOC theory; throughout the life-span human development is open and not fixed (P. B. Baltes et al., 2006). This type of attitude to aged individuals has the potential for counteracting the disadvantages described by Erikson.

Culture is an underdeveloped research area in palliative care (Gysels et al., 2012b; Surbone et al., 2007). The need for exploring socio-cultural understandings of illness experiences and caring, and the need for incorporating cultural aspects in guidelines have been identified (Selman et al., 2014). This need is demonstrated in the Norwegian guidelines for palliative care (Norwegian Directorate of Health, 2013) where the role of culture has gotten little attention. The findings related to identifying older people with incurable cancer needing palliative care, as an emerging public health concern (S. Hall et al., 2011), confirm the need for attention to the role of culture in healthcare services, and socio-cultural understandings of illness experiences and caring (Gysels et al., 2012a; Gysels et al., 2012b). In agreement with studies on the role of culture in clinical contexts (DeMarinis et al., 2011; Kleinman, 1980), the results appeared to show that the illness reframing process, when linked to the existential dimension, led to changes in the other dimensions in the applied cultural framework. These include new constructions of illness and health, improved relating to the surroundings, and adjustments made in daily living. A basic assumption in Kleinman’s cultural framework (1980), which is central for the understanding of illness experiences, is that cultural analysis on the individual level also involves information on the national and local context levels. This
is because culture is intertwined in all aspects of human experience (Kleinman & Benson, 2006). In Paper III this was demonstrated to contribute to a more nuanced understanding of patients’ varied interpretations and modifications.

5.2 Critical reflection on the study

The section includes three parts in which method- and theory reflection are the primary ones. The third part includes reflections about what could have been done differently.

5.2.1 Method reflection

The presentation contains the following sections: internal and external validity, reliability, and reflexivity. The understanding of these terms are derived from Creswell (2009) and Malterud (2001a, 2001b, 2011).

5.2.1.1 Internal Validity

In the study validity was understood as: “to check for the accuracy of the findings by employing certain procedures” (Creswell, 2009, p. 190). The procedures for checking validity (Creswell, 2009, pp. 191-192) are marked as italics in the text.

In qualitative research, different methods are possible for the analysis. The choice is mainly related to the role of theory as to the degree it is employed for the interpretation of the data (Creswell, 2009). In this study, theory both represented the end point of the analysis and the lens for analyzing the data material. The concept double reading was used to illustrate the interrelation of the two. To combine the phenomena in the double reading implied comprehensive analyses, containing both strengths and weaknesses. The strength lied in the fact that the double reading brought insight into some of the complex and diverse elements in the participants’ expressed illness experiences. From a hermeneutical point of view this allowed for an in-depth understanding (section 3.3). The weakness was connected to the risk of over-valuing the selected theoretical perspectives, so that their shortcomings were underrated and biases overlooked. Another weakness was related to the text material itself. A central question was if the findings reflected what the participants strived for, or how they wanted to be regarded, more than how they more genuinely experienced living with incurable cancer. In qualitative studies like this, there is always the risk that participants underestimate, conceal and/or ignore problems. However, to differentiate these aspects from each other was not possible in this research. As demonstrated in Paper I under the subtheme ‘to name and handle decline and loss’, the participants also shared comprehensive narratives about their
health difficulties. In Paper II under sub-observation 4 this aspect was elaborated further within the SOC model.

A critique of the inductive approach here is related to the use of conceptual frameworks as a part of the preunderstanding. The role of theory in these approaches is frequently discussed in qualitative research in general (Creswell, 2009). As described in 3.6.1 the definition of palliative care from the WHO (World Health Organization, 2014 a), framed as the “biopsychosocioexistential” framework here, and the broad understanding of spirituality from the EAPC definition (Nolan et al., 2011), guided the questions and issues in the semi-structured guide. This had implications for the study, of which two are addressed here. First, the frameworks contributed to the variety in the sub-findings in Paper I. Second, they influenced the development of the operationalized existential meaning-making framework identified in Paper I and further adopted and applied in Paper II. Thus, the framework was not entirely inductively based. Rather, it was constituted by certain questions from the guide. During the data-driven analysis the answers to the questions were grouped in open categories, these being shaped and defined by the participants’ illness experiences. There was wide variation within each concern in the framework. For instance, this was seen in the content of the three types of belief frames: atheistic/humanistic, religious and spiritual. When interpreted in this way the existential meaning-making framework functioned for the theory-driven analysis. In a qualitative study like this one, investigating meaning phenomena, pure observation, without any conceptual structure such as in grounded theory was seen as an inappropriate method.

A critique of the deductive approach used here is that the theory-driven analysis dominated at the expense of the data-driven one. More precisely, this happened to the subthemes in Paper I. Except for existential meaning-making the structure and content of the three other subthemes, that is to acknowledge the need for close relationships, to maintain activities of normal daily life, and to name and handle decline and loss, were not further examined. If this had been implemented other perspectives would have emerged from the data set, such as more detailed content descriptions of the participants’ daily life.

The strategy of triangulation was employed to some degree in relation to what Malterud (2011, p. 191) describes as “observer-triangulation” and “theory-triangulation. “Observer-triangulation” concerned the collaboration in the interdisciplinary research group for the data analyses, discussing and agreeing on the development of codes, categories, and findings. In this way, high inter-rater reliability was accounted for in the process. “Theory-triangulation” involved the use of different theoretical perspectives on the same data material as seen in
Paper II and III. In turn, the respective findings were seen together and summarized in the main finding (5.1.1).

To use member checking by sending parts of the product such as main themes or analysis to the participants was not implemented in the study. In this way the accuracy would have been better determined. However, a problematic aspect to consider was the ethical difficulties involved in the follow-up of participants since some experienced adverse health decline with a high probability of short life expectancy. A form of member checking took place in the interview situation, understood as central for the dialogical validity. When the participants had reflections that lasted over some time a summary was given, asking if this was what they meant. This gave the participants the opportunity to respond, correcting and/or nuancing their reflections.

Detailed descriptions of the findings were given in Paper I and II to show the diversity and complexity in the participants’ experiences of living with incurable cancer. In Paper III the comprehensive analysis was extracted and summarized as case illustrations due to the word limit in the paper.

The main finding concerning illness reframing processes could have included problematic psychological interpretations such as denial and experiences of major loss, thus elaborating on how these factors negatively affected experiences of illness, disease, and care. However, negative or discrepant information was only included to some degree in Paper I and II due to the prominence of life-oriented adaptive strategies in the interview material. For the four cases in Paper III the reframing appeared to facilitate favourable cultural processes.

To spend prolonged time in the empirical field was accomplished to some degree in the preparatory work period (3.3). However, as further described in 5.2.1.4 this did not mean that an inside-perspective was achieved.

It was assumed that the collaboration with the second researcher reduced the influence of biases in the initial interpretation. The work of reviewing the field notes in order to enhance the accuracy and to give response after each interview had common features with the strategy of peer debriefing. However, since the second researcher also took part in the interviews, the interpretation was influenced by the cooperation with the primary researcher. Thus, there might be biases that were overlooked or concealed.

The use of an external auditor to review the entire project was not used in a strict manner. The research group read all the transcripts, and made the final decisions relating to the analyses. The primary researcher coded three interviews together with one member of the research group in order to check for inter-rater reliability, which proved to be high.
Furthermore, the study was presented in research groups, and at national and international conferences.

5.2.1.2 External validity

External validity, also termed generalizability in qualitative studies, “asks in what contexts the findings can be applied” (Malterud, 2001b, p. 484). Here the aspect of purposeful sampling is further elaborated.

In this study, common in qualitative research in general (Creswell, 2009), the sample was purposefully selected in order to give answers to the research question. The setting and the events occurring during the recruitment process are described in the section on data collection in 3.6. As to the inclusion criteria some aspects are further presented here. Halfway in the recruitment process the research team discussed saturation, interview adjustments, and adjustments in the inclusion criteria. Eleven interview transcripts were read by all the members in the group. At this time no adjustments were needed except for that of increasing the number of women as only two had been included. By having equal gender representation, the heterogeneity in the sample was strengthened. Finally, the interview material in the study was considerable, comprising 370 text pages from 21 interviews. In this situation, the qualitative data analysis programme NVivo was particularly helpful for structuring the material. The amount of text material prolonged the analytic period. In the project outline, the total number of participants was fifteen. Relevant journals in psychology were consulted, finding that 20 participants often was the lower limit for publishing qualitative articles. For this reason the guideline was followed.

The inclusion criteria focused on patients that were living at home and had not reached the terminal phase. Patients were not approached if they had problems with concentration, memory, and serious hearing problems. Due to the hustle at the recruitment sites, the head nurses or deputy may have selected patients they considered as positive and able to reflect about personal matters. In any case the requested patients had to be well enough to engage in the detailed and personal interview. Therefore, there was a probability that patients with more difficulties or fewer resources were excluded from the sample. For instance, as the demographic table shows, the social factor was very important. Eighteen of the 21 participants, eight women and 11 men, were still living with their partner. This number differed from that in national statistics, which showed that almost 50% of the woman aged 67 and over and almost 25% of the men were living alone (Statistics Norway, 2011).
A decisive factor in any type of research in palliative care is that the participants are troubled by fluctuating symptoms, sometimes leading to an abrupt worsening of the health condition. This type of unpredictability affected the recruitment process and the characteristics of the final sample.

To include participants with curable cancer was considered in order to ensure broadness, thus increasing the possibility of generating hypothesis. Due to the heterogeneity within the group of older people with incurable cancer and because the amount of research on this group was scarce, the limitation was seen as important and relevant. Another limitation was that of the small sample size, which is necessary for qualitative in-depth research, but which limits the generalizability of the results.

Before the recruitment period started a mix-method approach was considered. This was not in accordance with the original project outline, which solely included the qualitative method of in-depth interviews. Several instruments used in palliative care research in Norway were checked, finding that no instruments had been validated by 2011 on spirituality, existential issues or resilience. Two central instruments in use in palliative care in Norway were considered. The ESAS instrument (Helsebiblioteket [Health Library], 2014), which is recommended as a standard procedure in palliative care (Norwegian Directorate of Health, 2013), measures symptom intensity, including anxiety and sadness/depression. The other instrument called EORTC QLC-C30-PAL measures health-related quality of life (EORTC Quality of life, 2014). Since the possible recruitment sites employed these instruments, collaboration would have been necessary for comparing and reporting results for each patient. The validated instrument HAD (Hospital Anxiety & Depression Scale) was also considered (Helsebiblioteket [Health Library], 2014). The main reason for selecting the qualitative method was to investigate in depth the illness experiences from the patients’ point of view. For this reason the combination of inductive- and deductive approaches for the data analysis was seen as appropriate and sufficient.

A difficult issue concerned assessment of cognitive- and emotional functioning when including the participants. The conclusion was that these types of assessment had to be made by the principal healthcare professionals at the respective recruitment sites, those responsible for giving the first information about the study. In this way, the confidentiality concerning sensitive information could be secured. To make a thorough evaluation of each participant was not feasible in the clinical context, this being beyond the healthcare professional’s competence and role. Thus, to fully avoid including participants with cognitive and emotional problems that made them unsuitable for interview was impossible. However, this aspect did
not interfere in a problematic way. In this connection, the close collaboration with the healthcare professionals and having the second researcher during the recruitment process were of great importance, see section 3.5.

5.2.1.3 Reliability
Creswell defines reliability in qualitative research in the following way: “that the researcher’s approach is consistent across different researchers and different projects” (2009, p. 190). Based on recommendations by Gibbs, Creswell (p. 190) suggests four reliability procedures of which three were relevant for this study. The fourth procedure is coordinating communication, sharing analysis, and documenting meetings in team research.

The first procedure was to check transcripts to identify mistakes made during transcription. The fact that the same person transcribed all the interviews reduced the risk of changing transcription procedure along the way. After each interview, the current author listened to the tape-recorded interview while reading the transcript, checking for mistakes and errors.

The second procedure was to ensure that the same understanding of the codes during the coding was maintained. The four steps in the “systematic text-condensation” were of importance in this respect as they provided for a stepwise process where changes in meaning could be detected. Also, the theory-driven analysis with the two-step analysis allowed for this type of identification. The collaboration in the research group was important in this respect, reducing the risk of a substantially shift in meaning for both the data-driven and theory-driven analysis.

The third procedure was to cross-check codes that have been developed by different researchers. This was not relevant in the study as the current author was responsible for the coding. However, some alteration of code names and content areas did occur to increase accuracy of the codes and the larger categories. Creswell suggests intercoder agreement in this type of research, implying that another person cross-check the codes. As already noted the research group collaborated on the analyses. The coding process continued until a high level of inter-rater agreement was reached.

5.2.1.4 Reflexivity
The central question concerning reflexivity is how the researcher affects the research process (Malterud, 2001b, 2011). Other terms that describe this are researcher effect and bias. The discussion here is based on the hermeneutical perspective from Gadamer (2011), described in 3.3.
The project outline for the study prescribed a phenomenological approach to older people’s experiences of living with cancer and their existential issues. Also, the financial grants had been given for the project. The main focus was determined, but there was flexibility as to theoretical perspectives and sub-questions. Thus, the phenomenological approach provided for an open attitude to the participants’ experiences and the research process itself, which was paramount for the study’s findings and conclusions.

Self-knowledge can never be complete and so to obtain a full overview of presumptions, some of them described in 3.3.1, was therefore impossible. However, due to the hermeneutical situation the incompleteness was not related to deficiency in reflection. Rather, it emerged from what was historically pregiven (3.3.2), and from this condition the understandings were formed during the research process.

One of the presumptions described in 3.3.1 was related to the professional background of the current author, implying that preparatory work in the palliative care field was required (3.5). There were both advantages and disadvantages related to these conditions. Here the understanding of the hermeneutical term “horizon” (3.3.2) was central: “the range of vision that includes everything that can be seen from a particular vantage point” (Gadamer, 2011, p. 301). The professional background and the unfamiliar field of investigation contributed to “horizons” that were different from those of a researcher being familiar with the research field. Thus, the vantage points were from a more distant perspective than for a person working in palliative care. A n advantage was that this gave rise to other types of reflections and questions, mainly materialized in the selection of the theoretical framework presented in chapter 2.

A disadvantage was that an inside-perspective, consisting of “horizons” from the research field in terms of acquired knowledge and experiences, was not within reach. To detect and explore issues from these vantage points was an impossible task. A healthcare professional knowing the palliative care field in this way would have raised quite different questions and developed other understandings, thus engaging in another type of interpretation process within the hermeneutical circle.

5.2.2 Theory reflection
A critical reflection in relation to the use of theory in this study points to a generally good fit in terms of process and selection.

In Paper I the process-oriented conceptual framework ‘resilience repertoire’ from gerontology was selected (P. G. Clark et al., 2011), finding that it corresponded with the
participants' responses to the adversities. The framework provided for a comprehensive and
dynamic understanding of resilience, also supported by palliative care research on older
people (Nakashima & Canda, 2005; Pentz, 2008). It corresponded with the diversity of
psychosocial and sociocultural resources among the participants on an individual level,
identified in all the four subthemes. The subthemes reflected and amplified the factors that go
into the “resilience repertoire”: chronic and incurable illness, experiences from life history,
and meanings in life (P. G. Clark et al., 2011). The identification of the existential meaning-
making framework can be understood as contribution to the generation of theory in the
qualitative research perspective.

In Paper II the “resilience repertoire” framework was explored further by combining it
with the understanding of resilience described in the SOC model. An advantage of the SOC
model is that it is seen as a broad theory conceptually and that it can be applied to develop
insight into adaptation processes in a diverse range of conditions (P. B. Baltes et al., 2006;
Donnellan & O’Neill, 2014). However, as existential meaning-making had not been
elaborated in the SOC model or research, the modified SOC model, including an existential
meaning-making framework and function, and a growth as well as a restoration approach to
resilience, was seen as a contribution to addressing this gap. The findings confirmed that the
modified SOC model worked well as an analytic tool for the interview material.

In Paper III Kleinman’s cultural framework of clinical reality (1980), adopted as five-
dimensions cultural framework for palliative care in Scandinavia by DeMarinis (1998, 2003),
was here applied for the cultural and existential meaning-making analysis. As noted in the
introduction (1.3.1) the model was constitutive for the understanding of the term illness
experience in the study. Framing the different cultural dimensions in a clinical situation is a
dynamic process, as reframing and adjustments to the changing conditions have an on-going
impact on daily living. For understanding these changes the psychological term reframing,
rooted in the psychotherapeutic tradition (Mattila, 2001), was relevant. The understanding
was related to the participants and their illness experiences. Illness reframing, as related to the
existential dimension in the cultural framework, was seen as a central part of their
interpretation process for dealing with the difficulties.

5.2.3 What could have been done differently?
Here some reflections are made concerning what could have been done differently in the
study. To employ the validated instrument HAD (Hospital Anxiety & Depression Scale)
(Helsebiblioteket (Health Library), 2014) would probably have contributed to a better basis
for examining the aspect of psychic dysfunction in the participants and possible dysfunctional aspects in their existential meaning-making experiences. Yet, there is also the risk that this could have reduced the quality of the interviews due to the health situation of the participants. The interviews contributed with a rich and unique material the way it was conducted.

Due to the thick descriptions of the existential meaning-making experiences the operationalized framework could have been categorized differently. Still, due to the necessity to select a framework, it functioned for the variety of expressions in the actual clinical population in the Norwegian context.

To apply the SOC questionnaire (Freund & Baltes, 1998) would have strengthened the basis for the SOC model in palliative care. However, the importance of also including in this study a growth aspect to resilience and an existential meaning-making component points to the need for consideration of the effects of these components when using the SOC model for a palliative care population.
6 Contributions, Implications and Future research

The chapter contains three sections presented in the following order: contributions, implications, and future research. The associated sub-sections are presented under each section.

6.1 Contributions

Four themes are highlighted in relation to the study’s contributions: clinical psychology of religion, palliative care, existential information for everyone, cultural analysis. Hypotheses generated through the study are presented.

6.1.1 Clinical psychology of religion

Little attention has been paid specifically to the group of older people with incurable cancer in clinical psychology of religion in Scandinavian contexts. The study’s contribution lies in addressing this research gap. The multilevel interdisciplinary paradigm was understood as a way of approaching when conducting qualitative research in a clinical population. A single theory and conceptual framework were seen as incapable of capturing the diversity and complexity in the participants’ illness experiences. Furthermore, the paradigm acknowledges that valid explanations for the same phenomena can be made with multilevel data analysis both within psychology itself and outside by crossing the disciplinary boundaries. The application of the paradigm was accomplished by combining the inductive and deductive approaches, framed as the double reading.

6.1.2 Palliative care

The study is a contribution to palliative care research on older people. As noted in the introduction the main reason for selecting this age group seemed quite obvious in terms of addressing an under-researched group, also taking the growing number of older people in specialized palliative care contexts into account. As far as the current author knows, this is the first qualitative study in Norway on older people living with incurable cancer as a chronic disease and receiving specialized palliative healthcare. The findings from the inductive approach showed that the older people in the sample did not differ from younger age groups in their experience of being strongly connected to life in the present.

6.1.3 Existential information for everyone

Based on the understanding that every individual has an existential dimension and spiritual nature, and that the dimension includes a broad variety of individual expressions, the study
confirms the importance of including existential information from every patient. When added to the SOC model the study showed that meaning-making was not only important on a strategy level for managing limited resources provoked by the biological process in aging and the incurable cancer. It was also a vital resource for providing culturally-sensitive information about how meaning was interpreted and expressed. This type of information, well documented in cultural psychology (DeMarinis 2008), provides information for understanding psychological processes and psychosocial interactions related to meaning and counter-reactions against meaninglessness. In addition, it provides information about dysfunctional meaning processes.

6.1.4 Cultural analysis
The adopted cultural framework in Paper III worked well as an analytic tool, confirming the usefulness of this type of analyses when applied in the palliative healthcare field. Furthermore, the importance of cultural analysis for patient care and for understanding the existential dimension in the cultural framework as pivotal for negotiating changes in the other dimensions was confirmed. The approach is in line with the understanding of cultural- and existential information in research in Norwegian mental healthcare (DeMarinis et al., 2011; Ulland & DeMarinis, 2014), and in the recommendation in the Diagnostic and Statistical Manual of Mental Disorder (DSM-5) (American Psychiatric Association DSM-V, 2013), to use the ‘Cultural Formulation Interview’ with every patient.

6.1.5 Hypotheses
The following hypotheses here:
Like the general Norwegian population, persons with incurable cancer in palliative care have a variety of existential meaning-making expressions.
To integrate existential information with every patient will lead to a better coordination of palliative care service and improved well-being for patients.

6.2 Implications
The implications of the study’s findings are divided into four aspects: clinical psychology of religion, specialized palliative healthcare contexts, the WHO-definition of palliative care, and the Norwegian guidelines, and local context and national level.
6.2.1 Clinical psychology of religion

The combination of the SOC model and the existential meaning-making framework with the resulting comprehensive approach to resilience might provide a fruitful next step for theoretical developments in clinical psychology of religion. The application of the modified SOC model has the potential to facilitate interdisciplinary cooperation, and to contribute to the development of life-span courses for hospital chaplains and others that are working with psychosocial aspects and the existential dimension in palliative care.

6.2.2 Specialized palliative healthcare contexts

As described in 3.5 the preparatory work in the field context was crucial for gaining insight into the research field. A part of the insight was related to the business and the pressure at the recruitment sites. In fact, healthcare professionals at one of the recruitment sites have reported that the number of older people receiving palliative care has increased every year since the recruitment period. This is in line with the prognosis reported by the Cancer Registry of Norway (2015, p. 71). A central and difficult question is therefore how the healthcare professionals can make use of this knowledge under these challenging circumstances. A pitfall for dealing with the pressure is to give supremacy to the disease itself, and involving the medical system with its diagnostic classifications and specific treatment interventions, and the exclusion of the illness experiences of the patients. Kleinman addressed this narrowing focus on diagnosis at an early stage in the research (1978). In his latest writings (2013) he has become even more critical to developments, highlighting the importance of keeping caregiving central in health care, and focusing on the moral and emotional core of experiences related to human suffering. In this study the challenge was addressed by interpreting illness experiences from a person-centered perspective. Despite the challenging situation in palliative care the knowledge is largely applicable as it involves ways of approaching- and attitudes towards the patients. To include existential information with every patient and to focus on resources and resilience in order to strengthen the person’s own life resources are the main contributions to palliative care. The fact that the participants experienced that specialized healthcare contexts strengthened the link to life by prioritizing and providing person-centred care is encouraging for both healthcare professionals, leaders in clinical contexts, and health politicians. This may increase the awareness about the importance of a functioning welfare system.

Knowledge of the close relation between existential meaning-making and resilience is important for permitting older people to have an active voice in how meaning is made and
shared throughout the adaptation process as incurably sick. In research on chronic illnesses the SOC model was seen as a useful tool for healthcare professionals in order to help people in identifying and maximizing their personal goals and resources. The same approach is suggested for palliative care in the domain of existential meaning-making. Attention to the role of culture in health services and of the clinical process is needed for better understanding the patient’s framework of interpretations, and for identifying treatment-planning resources.

6.2.3 The WHO-definition of palliative care and the Norwegian guidelines

The study’s findings showed that insight into the participants’ resources was essential for understanding how they experienced the adaptation process as incurably sick. A relevant critique of the WHO-definition of palliative care (2014 a) is that this aspect is missing, while the term ‘problem’ is used twice. This might contribute to a one-sided focus on the approach to patients. The frame ‘cancer survivor’ has been suggested as the main concept for patients living with incurable cancer as a chronic disease (Payne, 2007). It includes recognition of the required adaptations, and of resilience, and the social implications for this group of patients. In this research, resilience and the holistic effects of cancer in line with the perspective accounted for in the WHO definition have been addressed as key domains (Rowland et al., 2013).

The main perspective, termed as the ‘biopsychosocioexistential’ framework, functioned for the identification of a broad range of issues in the daily living of the participants, also included the struggles as they were identified in every domain of the framework. The study supports the need for the development of guidelines relating to cultural aspects of palliative care (Selman et al., 2014). In the Norwegian guidelines for palliative care (Norwegian Directorate of Health, 2013) the cultural domain is just briefly mentioned. It is seen as essential to incorporate a cultural understanding of clinical contexts and patient’s experiences in line with the adopted Kleinman framework and the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association DSM-V, 2013).

6.2.4 Local context level and national level

A qualitative study like this one gives prominence to the voice of older patients, permitting them to have an active voice in how they make meaning and how this influences their adaptation process to being incurably sick. The person-centered perspective allowed for this to happen. This can increase the respect for the individual on a local context level. To consider how the study contributes on a national level is difficult. Multiple factors are involved in shaping the problematic tendencies in the western culture towards the aging
period (5.1.4). To counteract these tendencies seems almost impossible. Nevertheless, it is still important to highlight the need for including concepts and constructs that capture a sustainable ideal of the whole of life such as life span theory and the SOC model.

6.3 Future research

To apply the multilevel interdisciplinary paradigm from psychology of religion as a way of approaching theory at every stage of the research design when conducting qualitative research in a clinical population is recommended in future research.

As cultural contexts and their palliative care services differ greatly, further testing of the SOC model would increase both accuracy and comprehensibility of research findings. Further testing of the cultural framework used in Paper III in specialized healthcare contexts is important, as its results may provide essential information for the clinical process itself, and contribute to effective means for including the existential dimension in palliative care. The central role of the existential dimension in the medical anthropological cultural model, as well as the importance of existential meaning-making information for psychosocial processes, point to the urgency for palliative care, especially in secular contexts such as Norway, to find a way to operationalize an approach to accessing this information in research and also in the clinical process. In this respect the impending public health need for palliative care for the elderly coincides with the public health promotion need to access cultural- and existential information in clinical populations for research and treatment planning (DeMarinis, 2008; DeMarinis et al., 2011).

The survivorship research field is growing (Rowland et al., 2013). Probably, it will affect palliative care research in terms of bringing insight into the key domains of resilience and the holistic effects of living with incurable cancer as a chronic disease. This may contribute to the emergence of new research areas. In this connection, research on older people should be prioritized.

Why is it important to obtain knowledge about the meaning of older people’s experiences of living with incurable cancer? Why is such knowledge important to obtain within healthcare? Lindseth and Nordberg (2004) argue that research on the meaning of lived experience in healthcare contexts is important because it may awake an awareness of unfortunate meanings or practices we are a part of, also referred to as discourses. This might lead to fruitful discussions and discourse improvements. What are the discourses in society and in public
healthcare in relation to older people with incurable and chronic diseases? This question seems to be of major importance for the future. Research on the discourses in public healthcare systems should be prioritized as they might represent barriers that contribute to the sparse amount of research on this age group. The identification and exploration of discourses will affect how we understand, interpret, and meet the challenges of the aging population.
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