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ELDERLY PERSONS LIVING WITH CANCER

Quality of life and lived experience

Bente Appel Esbensen

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<p>Over the coming decades, the numbers of elderly will increase, and through improved lifestyles and better treatment longevity has increased, and with it, the risk of contracting cancer. How elderly people live with cancer has until now attracted limited research. The overall aim of this thesis was to investigate the QoL of elderly persons from the time of a cancer diagnosis through the following six months. The aim was further to investigate changes in QoL over time in relation to type of cancer, age, socio-economic conditions, ability to perform Activities of Daily Living (ADL), contact with the health-care system, social network and support, and hope. Moreover, the aim was to illuminate the lived experience of getting cancer in old age. The study had both a quantitative and a qualitative part. The quantitative part was a follow-up study of 101 individuals (65+) recently diagnosed with cancer (74 women, 27 men), but was reduced to 75 (57 women, 18 men) by the six-month investigation point. QoL of newly diagnosed persons with cancer aged 65 years were investigated at baseline, and three and six months after using: EORTC QLQ-C30, Katz ADL-Index, Nowotny's Hope Scale and the Interview Schedule for Social Interaction (ISSI). The follow-up study was based on an interview schedule performed as three structured interviews. In the qualitative study, a descriptive phenomenological method was used to investigate 'the lived experience of getting cancer in old age'. In total, 16 persons, all recruited from the follow-up study, (aged 65+, mean age 76 (range 68-83)) with cancer were interviewed based on open-ended interview.</p> <p>Factors associated with low QoL at baseline were 'no other incomes than retirement pension', 'low level of hope', and 'lung cancer'. In addition, 'needing more help in activities of daily living', 'getting help from grown-up children' and 'needing help with PADL (Personal Activities in Daily Living)' were associated with low QoL. No significant changes were found in QoL from baseline to three months, while perceived social network deteriorated significantly. Dependency, reduced financial circumstances, and low level of hope were significantly associated with low QoL at the three-month follow-up. Fatigue was the most reported symptom at baseline and at three and six months. Emotional function improved significantly during the six first months, and complaints of nausea and vomiting decreased significantly. Support from grandchildren increased significantly. 'Contact with district nurse' at baseline predicted deteriorated QoL from baseline following six months, as well as 'low level of hope' and 'needing more help in daily living'. About 30% of the total sample deteriorated in QoL from baseline to 6-month follow-up. The findings in the qualitative study showed the essential meaning of the lived experience to be 'Illness as a turning point marking old age'. This was represented by three essences: 'Illness means losing control', 'Disturbing the family balance' and 'Life and death suddenly apparent'. These three essences were signified in seven constituents: getting cancer meant being forced into the role of a patient, losing control, and being dependent on health care. Balancing one's own needs and burdens with the needs and uncertainties of family members became essential; as a parallel to being conscious of dying and death, hope and enjoyment of life became vital.</p> <p>The majority of the participants showed an ability to adjust to the new condition. However, about one third had deteriorated in QoL by the significant ≥ 10 units at six-month follow-up, and clinical practice needs to pay specific attention to the most vulnerable groups of elderly persons with cancer. The most vulnerable stood out as those with advanced disease and decreased hope, those with increased need of both formal and informal assistance, those with reduced financial means and those with lung cancer, and thus they need specific attention from health care professionals. In addition, health care professionals need to be conscious that the elderly with cancer are a heterogeneous group. Therefore, it is important to identify the specific meaning that the cancer has for the individual, and to understand the particular abilities he or she has to adapt to the illness and the process of growing old as a part of their life.</p>		
Key words: elderly, age 65 and over, cancer, lived experience, QoL, ADL, social network and support, hope, EORTC QLQ-C30, Katz ADL-Index, ISSI, Nowotny's Hope Scale, phenomenology		
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Date February 28, 2006

Department of Health Sciences, Faculty of Medicine, Lund University, Sweden,
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ELDERLY PERSONS LIVING WITH CANCER

Quality of life and lived experience

Bente Appel Esbensen



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To Elias, Alma, Valdemar and Preben
– and to my parents, Ida and Andreas,
always reminding me of the essence of life.

*Den er ikke succes, sundhed og vellykkethed.
Livskvalitet går også med krykker og sidder i en kørestol på et plejehjem.
For livet kan være værd at leve for hvem som helst og hvor som helst.
Hvem der egentlig er livskvalitetens største modstander er meningsløsheden.*
Bjarne Lenau Henriksen, præst



Der var engang en smuk sommer morgen, på et af de smukkeste steder i Danmark, at træets fine symbolik blev klart for mig i forhold til denne afhandling. Hvis store, gamle træer kunne fortælle, ville de kunne berette om store som små hændelser gennem mange år med årstidernes skiften. Det er herfra inspirationen kom til at kalde denne afhandling for *'PROJEKT ASK': Aldring, Sygepleje og Kræft*.

Og om træet ASK siges der: Asketræet er et værdifuldt træ i Nordens skove. Denne afhandling er resultatet af et værdifuldt nordisk samarbejde: deltagerne i undersøgelsen er alle fra Danmark, forskeruddannelsen er gennemført i Sverige, og mange gode "forskervenner" fra Norden er det blevet til gennem årene. ASK-træet er set helt op til 40 meter højt, kan blive 200-300 år gammelt, og vokser bedst på en fugtig og næringsrig muldbund. ASK er på mange måder et symbol på et langt liv som mange mennesker idag får lov at leve. Et liv som har slået store, stærke og kraftige rødder og som bærer en flot og prætig krone, der vidner om livets fantastiske vidløftighed. Et stærkt netværk af grene, store som små, stærke som svage, tykke som tynde symboliserer menneskelivets styrke og svagheder, der altså bedst udfoldes når de rigtige betingelser for vækst er tilstede her i livet.

ASK følger årstidens rytme, og er dog samtidig særegen ved at dens frugter sidder i klaser på træet langt ud på vinteren. Alle deltagerne i undersøgelsen blev interviewet i deres 'livs efterår', og for nogle nåede 'vinteren' også at komme. Fælles for deltagerne var et ønske om at mærke livets puls og bære frugt helt til livets ophør. Kræftsygdommen blev et vendepunkt i livet og en markering af alderen, og der var fortsat et indtrængende ønske om at leve og at bære frugt her livet, selvom livets vinter kom nærmere.

ASK er karakteriseret ved at være et stærkt og elastisk træ. Deltagerne i dette studie viste sig i stor udtrækning af være seje, stærke og fleksible. Det var der også brug for. At få kræft som ældre er et vendepunkt som repræsenterer en grænsesituation og markering af: tab af helbred, af funktioner, af relationer, af håb og måske endda af livet. Men det er også muligt at rejse sig og genvinde troen på livet, vende blikket mod de opgaver der ligger foran en, også selvom man er blevet ældre og har fået kræft. I den forbindelse kan sygeplejefaglig indsats gøre en forskel. Det er hvad denne afhandling handler om.

Lund, Februar 2006
Bente Appel Esbensen

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ABSTRACT

Over the coming decades, the numbers of elderly will increase, and through improved lifestyles and better treatment longevity has increased, and with it, the risk of contracting cancer. How elderly people live with cancer has until now attracted limited research. The overall aim of this thesis was to investigate the QoL of elderly persons from the time of a cancer diagnosis through the following six months. The aim was further to investigate changes in QoL over time in relation to type of cancer, age, socio-economic conditions, ability to perform Activities of Daily Living (ADL), contact with the health-care system, social network and support, and hope. Moreover, the aim was to illuminate the lived experience of getting cancer in old age. The study had both a quantitative and a qualitative part. The quantitative part was a follow-up study of 101 individuals (65+) recently diagnosed with cancer (74 women, 27 men), but was reduced to 75 (57 women, 18 men) by the six-month investigation point. QoL of newly diagnosed persons with cancer aged 65 years were investigated at baseline, and three and six months after using: EORTC QLQ-C30, Katz ADL-Index, Nowotny's Hope Scale and the Interview Schedule for Social Interaction (ISSI). The follow-up study was based on an interview schedule performed as three structured interviews. In the qualitative study, a descriptive phenomenological method was used to investigate 'the lived experience of getting cancer in old age'. In total, 16 persons, all recruited from the follow-up study, (aged 65+, mean age 76 (range 68-83)) with cancer were interviewed based on open-ended interview.

Factors associated with low QoL at baseline were 'no other incomes than retirement pension', 'low level of hope', and 'lung cancer'. In addition, 'needing more help in activities of daily living', 'getting help from grown-up children' and 'needing help with PADL (Personal Activities in Daily Living)' were associated with low QoL. No significant changes were found in QoL from baseline to three months, while perceived social network deteriorated significantly. Dependency, reduced financial circumstances, and low level of hope were significantly associated with low QoL at the three-month follow-up. Fatigue was the most reported symptom at baseline and at three and six months. Emotional function improved significantly during the six first months, and complaints of nausea and vomiting decreased significantly. Support from grandchildren increased significantly. 'Contact with district nurse' at baseline predicted deteriorated QoL from baseline following six months, as well as 'low level of hope' and 'needing more help in daily living'. About 30% of the total sample deteriorated in QoL from baseline to 6-month follow-up. The findings in the qualitative study showed the essential meaning of the lived experience to be 'Illness as a turning point marking old age'. This was represented by three essences: 'Illness means losing control', 'Disturbing the family balance' and 'Life and death suddenly apparent'. These three essences were signified in seven constituents: getting cancer meant being forced into the role of a patient, losing control, and being dependent on health care. Balancing one's own needs and burdens with the needs and uncertainties of family members became essential; as a parallel to being conscious of dying and death, hope and enjoyment of life became vital.

The majority of the participants showed an ability to adjust to the new condition. However, about one third had deteriorated in QoL by the significant ≥ 10 units at six-month follow-up, and clinical practice needs to pay specific attention to the most vulnerable groups of elderly persons with cancer. The most vulnerable stood out as those with advanced disease and decreased hope, those with increased need of both formal and informal assistance, those with reduced financial means and those with lung cancer, and thus they need specific attention from health care professionals. In addition, health care professionals need to be conscious that the elderly with cancer are a heterogeneous group. Therefore, it is important to identify the specific meaning that the cancer has for the individual, and to understand the particular abilities he or she has to adapt to the illness and the process of growing old as a part of their life.

ABBREVIATIONS

ADL	Activities of Daily Living
AVAT	Availability of Attachment
AVSI	Availability of Social Integration
CGA	Comprehensive Geriatric Assessment
CI	Confidence Interval
CPR	National Central Personal Registry
EORTC QLQ-C30	European Organisation of Research and Treatment of Cancer Quality of Life Questionnaire
GP	General Practitioner
HRQoL	Health-Related Quality of Life
IADL	Instrumental Activities of Daily Living
IQR	Interquartile Range
ISSI	The Interview Schedule for Social Interaction
NHS	Nowotny's Hope Scale
OR	Odds Ratio
ON	Oncology Nurse
PADL	Personal Activities of Daily Living
RN	Registered Nurse
SD	Standard Deviation
SOC	Selective Optimisation with Compensation
QoL	Quality of Life
WHOQOL	World Health Organisation Quality of Life

ORIGINAL PAPERS

This thesis is based on the following papers, which will be referred to the text by their Roman numerals:

- I Esbensen B.A., Østerlind K., Roer O. & Hallberg I.R. (2004): Quality of life of elderly persons with newly diagnosed cancer. *Eur J Cancer Care* **13**, 443-53.
- II Esbensen B.A., Østerlind K., & Hallberg I.R.: Quality of life of elderly persons with cancer: a 3-month follow-up. *Accepted for publication in Cancer Nursing*, 29 (3) 2006
- III Esbensen B.A., Østerlind K., & Hallberg I.R.: Quality of life of elderly persons with cancer: a 6-month follow-up. *Submitted to Scandinavian Journal of Caring Sciences*, 2005
- IV Esbensen B.A., Swane, C.E., Hallberg I.R. & Thome, B.: The lived experience of getting cancer in old age. *Submitted to International Journal of Nursing Studies*, 2006

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INTRODUCTION

Understanding the quality of life (QoL) in persons newly diagnosed with cancer and to obtain an understanding of the illness trajectory of how the person manage the situation is valuable to provide the best possible care. This thesis is based on the assumption that, to improve QoL, it is essential to understand what it means to get cancer in old age. Over the coming decades, the numbers of elderly will increase, and, due to improved lifestyles and better treatment, these people will live longer. In addition, cancer is an age-related disease: over 60% of new cancer cases and two-third of all cancer deaths occur in people 65 years and older. Despite this past decade's growing interests in geriatric oncology, relevant knowledge remains limited (Balducci and Extermann, 1999). The situation of elderly persons with cancer cannot be understood as simply a function of chronological age, but has to be perceived as a process with certain individual characteristics of events and situations. Aging is in most cases associated with a progressive decline in functional abilities, social network and support, increased use of services from the health-care system and limited life expectancy (Overcash and Balducci, 2003). However, aging is also related to new possibilities in life, and several factors may contribute to changes in QoL. These include activities of daily living, social network and support, contact with the health-care system, socio-economic conditions and individual characteristics such as outlook on life.

Previous literature has primarily been concerned with insufficient geriatric assessment and the fact that elderly people have been excluded from participation in clinical trials. However, there is a need to focus on the relation between geriatrics and oncology (Boyle, 1994, Ferrell, 1999) to achieve a deeper understanding and insight in the special needs of elderly persons with cancer (Boyle, 2004, Boyle, 2003, Hansen, 1998). There is also a need to obtain insight into the experience of getting cancer in old age. Health care professionals have to deal with the challenge of providing care to a growing number of patients who have unique care requirements. This thesis is an attempt to add to the understanding of QoL in elderly persons with cancer, and their experience of getting cancer in old age.

BACKGROUND

To understand the complexity of an elderly person living with cancer, a comprehensive approach (towards the elderly person) must cover not only physiological elements, but also specific elements that are of significance to the elderly, e.g. daily functioning, social relations, ethics and QoL as well as the capacity of the person to manage the day-to-day requirements of life. These elements have been pointed out by Michel (2005) as 'The Geriatric Core'.

Aging

The aging process

The age at which a person is considered 'elderly' varies in the literature, and no consensus exists about how to define the word. Over 65 has traditionally been chosen as a cut-off,

because for Western cultures it represents retirement from work and the start of some sort of assistance from the state being available (Redmond and Aapro, 1997). The age-limit for the productive working life at 65+ (Sachs, 1987), is naturally followed by changes in income (Balducci et al., 2003). Bytheway (1995), however, argued that old age and aging are no more than ways of thinking the 'elderly' could be viewed as a socially constructed category that makes it legitimate to separate and manage people by virtue of their chronological age. Chronological age does not accurately describe the functioning of a person and the changes that aging bring about. Physiological aging implies a progressive decline in function that becomes more evident as a person ages. However, the rate of physiological aging differs between individuals (Ebersole and Hess, 1998). Furthermore, it differs not only between individuals but also within different systems of the same person (Eliopoulos, 1997). In the literature, it is common to view 'elderly' divided into three groups: 'young-old' (65-74), 'mid-old' (75-84) and 'old-old' (85+) (Given and Given, 1989). Definitions and categories of 'elderly' could be thought of as part of a specifically statistical or demographic way of looking at things (Bailey and Corner, 2003). Aging cover a period of 30 to 40 years and circumstances during that time span differ very much. Also, the variation in how a person grows old is large. Within the aging period, a person may experience different phases and changes regarding both growth and decline in several function such as physical, psychological and social changes.

Geriatric medicine has been defined as the branch of medicine that concerns itself with the aging process. It includes: prevention, diagnosis, and treatment of health care problems in the aged; and the social and economic conditions that affect the health care of the elderly (Duthie, 1998). Geriatric clinicians acknowledge that chronological age is a poor descriptor of a patient's functional status. The natural history of illnesses and comorbidity within a person, the person's functional status, or the social context (e.g. economic resources, family support) of the person may, according to Duthie (1998), be a better determinant of outcome. Providing treatment and care for the elderly is supported to be a comprehensive system of care that embodies the principles of adult medicine, modifies these principles to accommodate changes related to aging, and employs an interdisciplinary approach when needed (Duthie, 1998).

Aging from a biological/medical perspective

The medical perspective usually focuses on physical and cognitive changes, loss of function and diseases. However, although physical aging is inevitable, physical disabilities and dependency are not (Atchley, 1997). As people age, their physiology and metabolism change in ways that may affect the body's ability to respond effectively to the stressors imposed by cancer and other diseases. Age may be associated with loss of cardiac muscle fibres because of ischemic or degenerative changes and loss of cardiac function. Similarly in the kidneys there is a decline in glomerular filtration rate and reduced ability to concentrate urine, making drug excretion more problematic (Ebersole and Hess, 1998). Changes in liver function are less predictable and the ability of the liver to metabolise drugs may not be greatly affected by age. However, there is a decrease in gastric acid production and functional absorption, which, together with increasing use of antacids, may significantly alter the absorption and metabolism of oral cancer medication. Reduction in the reserve capacity of the bone marrow beyond the age of 70 may reduce its ability to respond to stresses such as blood loss or infection or to sustain or recover

adequate numbers of circulating cells after chemotherapy. Reduced tissue repair, particularly of skin and mucosal tissue, will also affect the ability to tolerate radiotherapy. Another consideration is the age-related changes to the eyes and ears which can affect the elderly person's ability to communicate optimally with health care professionals (Ebersole and Hess, 1998, Eliopoulos, 1997).

Biological changes, losses in physiological capacity and reduction in general reserve capacity must not be mixed up with diseases and diagnoses that, in addition to the aging process, lead to complexities. Nevertheless, once a certain disease is verified the trajectory may be complex due to losses in physiological capacity and specific functions. It can be difficult to differentiate age related changes from symptoms and signs of disease. There is a high incidence of comorbidities in the elderly and the number of comorbidities increases with age (Yancik et al., 2001). Cancer may just be one of several diseases. Another element of biological change is fatigue, related both to cancer and to aging (Tralongo et al., 2003). Fatigue is a state of tiredness, strain and weakness associated with a feeling of exhaustion (Tralongo et al., 2003). Cancer-related fatigue and fatigue related to aging might be qualitatively different from the fatigue occurring due to exercise or stress. It is a symptom developed over time, which does not disappear with, for instance, resting, and can affect daily living. According to Avlund, (2003) fatigue is an indicator of 'how we are aging'. In a prospective study with an 18-month follow-up (age 74-80; n=1396), fatigue in daily activities became an important risk factor for onset-impaired mobility. Fatigue was not an indicator of old age or necessarily associated with old age. Instead fatigue was an indicator of how a human being is growing old and is a profound symptom that must be taken seriously earlier in life, as it might be a sign of future disease and weakness (Avlund et al., 2003).

Nonetheless, a significant part of the biological-medical model is the need for a precise diagnosis to provide the best possible treatment for the person (Michel, 2005). While physical aging involves loss of capacity and disease, the key question is how much capacity is left (Atchley, 1997), and the question is how the elderly person is able to manage daily functioning followed by diseases. According to Michel (2005) it is important that assessment of functional status covers several interactive dimensions such as gait/balance, medical dimensions, nutrition, cognition, environment, financial position, social support, and spirituality. Such an assessment contributes to essential knowledge about how the elderly manage physical changes; it needs to end up with a management plan.

Aging from a psychological and social perspective

Awareness of aging from a psychological and social perspective is important to obtain an overall view of the situation of an elderly person. The social-psychological perspective looks at the complex ways in which individuals internalise the demands of society and how they accept their social context (Bengtson and Haber, 1975). The psychological perspective is concerned with how a person relates and reacts to environmental demands, and the stresses of life. Issues within the psychological perspective are vision, intelligence, thinking, cognitive issues, memory, problem solving, reaction, personality, time and learning ability (Atchley, 1997). Constraints in physical ability and ADL, dependency (financial, social and transport), comfort (loneliness, emotional equilibrium), loss of status and role, and future uncertainty about survival and impending treatment have been

emphasised as leading to psychological problems in the elderly (Gosney, 2005). Previous aging models and theories within psychology have focused solely on a simplified view of the individual's development and a passive view of the individual, where basically the elderly were understood as victims of biological and social influences (Atchley, 1997). Nevertheless, those models mark a paradigm shift and emphasise the importance of understanding the individual as a part of the environment, and that several factors correlate in aging, and of striving to understand the elderly as active people rather than being passive recipients for negative influences (Wortman and Silver, 1990). From a social perspective aging is concerned with how experiences and changes in roles impact on social life as chronological age increases (Bengtson and Haber, 1975). Changes in social life in the elderly imply losses of life-long friendships (Bengtson and Haber, 1975), however, they also imply changes in family roles (spouse, parenthood and grandparenthood) and in friendships (Atchley, 1997). Also retirement plays a big part in aging (Atchley, 1997), as it often leads to declining income and restrictions in financial resources. However, withdrawal from the labour market opens up for new possibilities as an increasing range of health care services (Bernard et al., 2000).

Some of the earliest theories about psychological and social perspective were the 'disengagement theory' (Cumming et al., 1960), which claims that aging includes withdrawal and reduction in social activities. A theory of psychological and social perspective with an opposite approach came from Baltes & Baltes (1993). According to them, being elderly involves potential challenges for the person. It could be seen as a process whereby loss of biological, mental, and social reserves and aging conjures up a picture of decline, and approaching death, whereas success imply benefit (Baltes and Baltes, 1993). The way an elderly person becomes aware of the changed circumstances, and how this awareness is managed, is decisive for the way the individual continues in life. Baltes & Baltes (1993) contributed with a psychological metamodel that attempts to represent scientific knowledge about the nature of development and aging, with the focus on successful adaptation. The model takes gains and losses jointly into account and pays attention to the great heterogeneity in aging. The model also consider successful mastery of goals in the face of losses common to advanced age and suggests that elderly people may facilitate the aging process by adopting the principle of Selective Optimisation with Compensation (named SOC) (Baltes and Baltes, 1993).

The first element *selection* refers to the increasing restriction of a person's world to fewer domains of functioning through losses in the range of adaptive potential (Baltes and Baltes, 1993). The adaptive task requires both the person and society to concentrate on those domains that are of high priority and involves a convergence of environmental demands and individual motivations, skills and biological capacity. Selection denotes a reduction in the number of high-efficacy domains, and can involve new or transformed domains and goals in life. Thus, the process of selection implies that an individual's expectations be adjusted to permit the subjective experience of satisfaction as well as personal control. *Optimisation*, the second element, refers to the view that people engage in behaviours to enrich and augment their general reserves, and to maximise the quality and quantity of their chosen life styles. According to Baltes & Baltes (1993) the elderly continue to be able to implement this optimising process. The third element, *compensation*, results also from restrictions in the range of plasticity or adaptive potential (Baltes and Baltes, 1993). It becomes operative when specific behavioural capacities are

lost or are reduced below a standard required for adequate functioning. The element of compensation involves aspects of the mind and technology. Psychological compensatory efforts include, for instance, the use of new mnemonic strategies when internal memory mechanics or strategies are insufficient. The use of a hearing aid would be an instance of compensation by means of technology (Baltes and Baltes, 1993). The SOC process is likely to engage throughout life, and it probably takes on a new significance and dynamic in old age (Baltes and Baltes, 1993), independent of disease. The SOC theory emphasises the process of aging as a developmental process. The processes are however not static, but change over time. Existing theories about aging focus on losses and possibilities. However, it is the way a person develops that is decisive for the quality of aging rather than primarily the absence of diseases and decrease in function. Though the situation is dependent on the actual situation and how a person is able to accept the transition to a new phase in life as aging (Schumacher and Meleis, 1994).

Elderly persons with cancer

The presence of diseases and comorbidities increases with old age and the onset of cancer is one of many disease related to aging. In the years to come an increasing number of elderly people in Western societies will be diagnosed with cancer. The elderly population (age 65+) is expected to grow by 2.5% growth rate per year, and cancer disproportionately affects those aged 65+, so the number of elderly people diagnosed with cancer is expected to rise in the future (Balducci and Extermann, 2001). The peak is expected to occur after 2030 (Moller et al., 2002). In the USA 63% of all new cancers in 1990 occurred in people aged 65+ (Davesa and Hunter, 2000). For Denmark, people with cancer represent the majority of the population with cancer: nearly 60% of all cancer deaths occur in persons 65+. Due to aging of the Danish population ageing, the number of elderly (75+ years of age) cancer patients in Denmark (population 5.5 million) is expected to increase from 8,009 aged 75+ in year 2000, to 8,301 in 2005, and 11,118 in 2015 (Moller et al., 2002). Breast cancer is the most frequent diagnosis in the USA in women, followed by colorectal cancer, lung cancer, gynaecological cancers and malignant melanoma (Coebergh, 2001), which is in accordance with data from Denmark (Hansen, 1998). The most frequent cancer diagnoses in men are prostate-, bladder-, lung-, and colorectal cancer, accounting for $\geq 50\%$ of all cancers in Denmark (Hansen, 1998). For both elderly men and women, a gender specific cancer has the highest incidence, ie prostate and breast cancer, respectively (Hansen, 1998).

The elderly are often presented in the health care literature as part of a process of deterioration; problems due to decline, and caring for elderly people may be thought of as 'adding to the burden' of health services (Bailey and Corner, 2003). Nevertheless, valuable knowledge about elderly persons with cancer, their views of life, and their ways of managing life with cancer has until now been scarce, though urgently needed. In addition, to the negative perspective towards elderly persons with cancer, issues concerning age-discrimination within geriatric oncology have been raised. In an exploratory study (46 cancer patients, age range 29-88 years (median 61)) Tishelman (1993) found that, although age-related issues were not directly addressed by the interviewer, they were frequently commented upon by the patients. Some of the comments were seen in patients' perceptions of the response of the professional health-care system. The elderly patients

reported that they had less frequent contact with specialized formal resources, and perceived less sense of engagement and concern from the professional health-care sector (Tishelman, 1993). Also in a qualitative study (aged 75+, n=10) elderly persons with cancer said that they experienced mistreatment or neglect due to their age (Thomé et al., 2004). However, their life was not solely sorrow and suffering, as the participants also drew the strength to live with cancer in old age. Kearney et al, (2000) who performed a descriptive survey study (n=197) also stressed that health care professionals seem to bring negative attitudes to elderly persons with cancer, and that these attitudes need to be changed. Nevertheless, it is urgent to pay attention to the perspective of the elderly with cancer, and there is a need to focus on their expectations and desires for treatment, life and future. The starting point needs to be to understand the differences between individuals, their responses, how they deal with the new situation and their interpretation of their illness.

Cancer diseases, treatment and clinical trials

The major aim of this work was to improve understanding of the significant needs of elderly persons with cancer. Coverage was restricted to patients diagnosed with one of the four most frequent cancers in order to get a representative and reasonably homogeneous study sample. The major invasive cancers in the elderly are breast, lung and colorectal cancer followed by gynaecological cancer (Luggen, 2000). In this way it is possible to improve understanding relevant to the elderly with cancer by focusing on obtaining knowledge in QoL and other issues of significance for these diagnoses. The typical treatment offered for the above four categories of cancer involves surgery, chemotherapy and radiotherapy; often used in combination. Lung cancer differs in pattern of treatment, as chemotherapy may often be the sole form of treatment for some types. In addition, to the above treatments, breast cancer is often treated with hormone therapy. The illness trajectory for all four groups might be significant in time (five years and more). However, inoperable lung cancer is characterised by short survival (median 6-8 months) after diagnosis.

Breast cancer is a common-disease in the elderly and is the foremost cancer diagnosis, and the second leading cause of cancer-related death, after lung cancer (Kimmick, 2000). In Denmark 2.169 women out of 8.838 women (aged 60) were diagnosed with breast cancer in 2001 (2005). The exact cause of breast cancer is not known, but several risk factors have been identified such as age at first child birth, duration of lactation, age at menarche and at menopause, postmenopausal hormone replacement therapy, night work, and a family history of breast cancer (Reigle, 2000). Cancer treatment includes surgery, radiation therapy, chemotherapy, and with similar strategies in all age groups (Kimmick, 2000). According to Kimmick (2000), clinical trials focusing on the role of adjuvant treatment in older women with breast cancer are of paramount importance inside and outside the clinical trials setting.

Colorectal cancers primarily occur in persons aged over 65 years (Neilan, 2004), and are the third most common cause of death from malignant disease. In Denmark 1.496 men and 1.435 women (aged 60+) were diagnosed with colorectal cancer in 2001 out of 22.665 people who were diagnosed with all cancers (aged 65+ years) (2005). Diagnosis of colorectal cancer is often made late in the disease process, which leads to poor survival

(Schneider, 2000). The cause of colorectal cancer is unknown, but research has revealed several risk factors including diet (fat, industrially processed meat products and alcohol), and genetic factors (Schneider, 2000). The World Health Organisation (WHO) has published guidelines for primary prevention of colorectal cancer (Neilan, 2004), and suggested that modification of diet and lifestyle may be helpful in preventing the development and progression of colorectal cancer. Screening asymptomatic older persons is most important for early diagnosis of colorectal cancer and decreasing mortality (Neilan, 2004). Surgery is the most important treatment for colorectal cancer. Surgical resection may be followed by adjuvant chemotherapy. In advanced disease, a number of palliative chemotherapy regimes are available (Neilan, 2004).

Gynaecological cancer is an important cause of mortality in women between the ages of 35-75 years, and the incidence of gynaecological cancer increases with age (Moore, 2000, Thigpen, 2004). In Denmark, 817 women out of 11.263 aged 60+ were diagnosed with gynaecological cancer (2005). Cancers arising in the female genitalia are among of the more common malignancies in women (Moore, 2000). Elderly patients with gynaecological cancers of the vulva, cervix, endometrium or ovaries appear to have a poorer prognosis than younger patients (Moore, 2000, Thigpen, 2004). Other than age, the most significant prognostic factors for ovarian cancer are disease stage and histological type (Thigpen, 2004). The most important determinant of prognosis, however, is the extent of disease at the time of diagnosis. Treatments of gynaecological cancer are dependent on type of disease and stage; and include surgery, radiotherapy and/or chemotherapy, single or in combination (Thigpen, 2004).

Lung cancer is the leading cause of cancer death in men and women (Luggen, 2000) The incidence is decreasing in males but still increasing in females (Grunberg and Bibawi, 2000, Luggen, 2000, Shepherd and Bezjak, 2004). In Denmark, 2.883 cases of lung cancer out of a total of 18.563 cancer cases were diagnosed in patients older than 60 years of age in 2001 (2005). Lung cancer has surpassed breast cancer as the leading cancer cause of death in women and accounted for 25% of all female cancer deaths in 1999 (Luggen, 1999). The risk of lung cancer in heavy smokers is 10-25 times greater than the risk in non-smokers (Luggen, 1999). Environmental and occupational exposure, such as to asbestos are other risk factors (Grunberg and Bibawi, 2000, Luggen, 2000). 75-80% of lung cancers are classified as non-small cell lung cancer (NSCLC). In total, 20% of lung cancers are small cell lung cancer (SCLC), which is an aggressive, rapidly growing neoplasm. Stage of diagnosis is the most important determinant of prognosis in lung cancer with median survival of 6-8 months for inoperable NSCLC and for SCLC (Grunberg and Bibawi, 2000, Luggen, 2000). Chemotherapy is the treatment of choice for inoperable NSCLC and for SCLC. Only 15-20% of Danish NSCLC patients are operable at time of diagnosis. Age is not considered a contra indication to surgical resection, chemotherapy or radiotherapy (Luggen, 2000).

Compared to younger people, the elderly often have a delayed diagnosis of cancer, resulting in it being at a more advanced stage at diagnosis, (Balducci, 2003). Discussions about screening in the elderly have not resulted in specific recommendations. Recent studies have shown that mammography screening in women over 65 resulted in better detection of early stage cancers than in the 50 to 64 year age group age (Lichtman et al., 1996). On the other hand, recent guidelines do not recommend the use of mammography

screening in women older than 75 years, because there is no evidence that it decreases breast cancer-related mortality (Kimmick, 2000). The elderly and their general practitioner often dismiss the symptoms as age-related without further investigation (Yellen et al., 1994). Once they are diagnosed, they often receive less aggressive treatment resulting in an increase in mortality from the cancer rather than comorbidities (Yellen et al., 1994). However the elderly with cancer are likely to accept treatment, including in trials, as often as younger patients (Yellen et al., 1994). Physicians' attitudes influence elderly cancer patients' decisions about whether to receive treatment or not, and in general they accept the physician's recommendations unconditionally (Slevin, 1991). Knowledge about the elderly with cancer may contribute to insight that can be useful in supporting the decision-making process.

It is unambiguous that some elderly cancer patients can derive significant benefit from combination chemotherapy (Shepherd and Bezjak, 2004), and some may not. Options of therapy cannot be dismissed without a careful evaluation of the stage of disease, comorbidities, and individual wishes for therapy (Grunberg and Bibawi, 2000). However, according to Unger (2004), only 25% of elderly cancer patients (>65 years) are participants in clinical trials, but represent 63% of the cancer population, i.e. the elderly are underrepresented in trials. Hutchins (1999) reported that, except from lymphoma, elderly persons (+65 years of age) were under-represented in clinical trials in 15 different types of cancer. Yancik et al. (2001) found that elderly American women with breast cancer were receiving less aggressive treatment, including fewer axillary node dissections, breast-conserving surgery or radiotherapy, than younger women. Pre-existing diseases such as diabetes, hypertension, stroke, gastro-intestinal or other health related problems result in less aggressive forms of treatment being prescribed, which is quite reasonable. Age alone, however, is a poor predictor of outcome in cancer treatment and is an inappropriate factor by which to exclude cancer treatment (Balducci and Extermann, 2001, Hutchins et al., 1999, Unger et al., 2004, Wymenga et al., 2001). Health professionals seemingly assume that elderly persons are unable to cope with aggressive forms of treatment despite evidence to the contrary. As a result, elderly cancer patients have been either over-treated or under-treated, and the symptom management is therefore often inappropriate (Anderson and Forman, 2004). Studies of outcomes from surgery, chemotherapy and radiotherapy suggest that the elderly are able to tolerate these therapies well and gain as much curative or palliative benefit from the treatment as their younger counterparts (Audisio, 2004, Audisio and Zbar, 2002, Donato et al., 2003, Green and Hacker, 2004, Patel and Zenilman, 2001, Pignata and Vermorken, 2004). Despite the increasing focus placed on cancer in the elderly, a prominent discrepancy exists related to age why that elderly people often receive less than optimal treatment and care (Kearney and Miller, 2000). According to Kearney and Miller (2000) 'ageism', the stigmatising effect of society's negative attitudes towards the elderly, leads to ethical dilemmas in cancer care. The fact that elderly patients with cancer have been refused the opportunity to participate in appropriate treatment represent an ethical dilemma (Kearney and Miller, 2000). However, to offer treatment to elderly persons with cancer also implies the ethical dilemmas whether to offer or not, whether to operate or not (Fabri, 2004). Ethical considerations are raised in treating elderly patients who have some degree of mental impairment. Patients have the right to agree to or refuse treatment to provide data for research and, if asked, to enter into a clinical trial or not as they choose (Redmond and Aapro, 1997). It emphasises how important it is to obtain knowledge about the elderly

with cancer, and how important it is to ascertain the patient's views regarding treatment and to include them in decision-making.

Psychosocial implications of cancer

Cancer is a disease with many manifestations, occurring at different sites of the body, and following different courses depending on the site and cell type (Ganz, 2004). The emotional impact of cancer will depend on a variety of factors, such as experience of diagnosis, the individual's perception of cancer and its meaning, the disruption the disease causes to normal life, the individual's personality and coping strategies (Wells, 2001). Cancer distresses family and friends as well as the person with cancer (Plant, 2001). For the elderly special issues add to the experience, and perhaps burden, of being diagnosed with cancer. These issues are according to Redmond & Aapro (1997) e.g. comorbidities, decreasing strength, health and vigour, sensory loss, mental deterioration, depression, adjustment to retirement and reduced income, adjustment to the deaths of spouse or siblings, other family members or friends, adjusting to new social roles (including loss of status), disability, dependency and facing death. Cancer in old age represents a complex set of challenges that the person has to manage at the same time as the ongoing process of loss and adaptation related to ageing. Such changes may be experienced as various transitions. Such transitions may be associated with feelings of uncertainty, emotional stress, interpersonal conflict and worry (Schumacher et al., 1999). However, the experience of long life may help the elderly to manage the situation better than younger patients. How people with cancer experience this complexity and adapt to the changed situation, using selective optimisation with compensation (SOC), is relatively unexplored. Insight into the experience of the elderly with cancer may enable us better to help future elderly patients in making their life transitions easier and in adapting to their changed situation.

Following a cancer diagnosis a person often has to deal with both the illness and the treatment, and at the same time to confront issues concerning an uncertain future and the meaning of life and death (O'Connor et al., 1990). The first couple of months after diagnosis may be particularly difficult due to the raising of existential issues related to life and death (Edgar et al., 1992, Weisman, 1976). The diagnosis is followed by shock after the realization that life cannot be controlled, that anxiety is a part of life, and that life cannot always be independent. Getting cancer is often traumatic experience, leading to crisis, physically, psychosocially, and existentially facing the inescapable reality of life (Jasper, 1949/1953). Many people today survive a cancer diagnosis, and it is necessary to understand cancer as a long-lasting disease (Benner and Wrubel, 1989, McCorkle et al., 1998). According to McGill (1993) 50% of all cancer patients (65+ years) (except for those with lung cancer) will live at least five years. Therefore, research is needed to explore the experience of elderly persons with cancer, how QoL is affected over time, by taking into account the impact of treatments, symptoms, and events in a person's life.

For health-care professionals cancer is an objective and assessable biological/pathological condition, while patients may often perceive it differently. With reference to Kleinman (1988), a person's perception of a disease is attributed 'illness'. This refers to the ways the disease is experienced and interpreted by individuals, and the cultural perceptions of symptoms and suffering. Illness concerns the lived experience of monitoring bodily

processes (Kleinman, 1988). According to Charmaz (1991) living with serious illness can catapult people into a separate reality. Many people who live with an illness, such as cancer, move between being immersed in it, and keeping it contained. For that reason, it is important to illuminate the experience of illness and to give voice to people who live with it. Living with serious illness means more than learning to live with it. It means struggling to maintain control over the defining images of self and over one's life. This struggle is grounded in the concrete experiences of managing daily life, grappling with illness, and making sense of it (Charmaz, 1991); to take on a subjective perspective gives insight in a person's lived experience about how people handle living with a serious illness. Health-care professionals' understanding of the process of growing old and of cancer is therefore essential for the elderly to adopt the right approach to elderly with cancer. A thorough understanding of the lived experience of people newly diagnosed with cancer and of the trajectory of growing old appears to be lacking, but is much needed to provide care adjusted to the individual's needs.

Factors with significant influence on quality of life

The ultimate goal of caring should be to enable elderly persons with cancer to maximise their QoL. However, a number of factors appear to add to the complexity of life of the elderly and in addition have a significant influence on their QoL, either positively or negatively, as summarised in Figure 1. Time is an important factor in QoL and together with changes in the progression of the illness.

Having lived a long and rich life may be seen as a resource on which the elderly with cancer can draw. Furthermore, such experience may contribute to QoL in a positive way. Changes in socio-economic conditions, such as withdrawal from the labour market, open up new possibilities in relation to social networks and leisure; marital contentment and good living conditions, as well as educational attainment may add to the positive experience of being elderly. Some elderly people can derive significant benefit from cancer treatment, with minimal complications, depending on type of diagnosis and treatment, which perhaps influences QoL significantly. The ability to manage daily living independently may also have a positive impact on QoL. Living with cancer inevitably leads to increased use of the health-care system, and receipt of satisfactory treatment, care and support may lead to feelings of comfort and relief. Develop valuable social relations and get sufficient support, independent of the size of network, may have a positive significant effect on QoL. Reserves of inner strength to cope with the demanding situation of getting cancer in old age are essential in retain decreased QoL; this strength may manifest itself through hope. The ability to focus on one's own resources, and efforts to maintain a given level of functioning, despite being newly diagnosed with cancer, may help to maintain QoL

Difficulties in adapting to the changed situation may decrease QoL. The various losses and occurrence of diseases that age brings may diminish QoL in elderly people with cancer. Changes in socioeconomic conditions, such as reduced income, loss of spouse and friends may reduce QoL in the elderly. Declining capacities, leading to dependency in ADL functions, are important indicators for reduced QoL. Increased calls on health care may perhaps be a threat to QoL. Elderly persons with cancer may be especially vulnerable

due to a decline in their social network and its support; this can lead to isolation and disappointment as needs cease to be met by their previous social network, leading in turn to decreased QoL. Reserved of inner strength to manage the difficulties of life and the absence of hope are a serious threat to QoL in the elderly with cancer. Difficulties in adapting to the new situation, such as focusing on losses instead of on the positive aspects of one's own resources, together with problems in obtaining a satisfactory level of functioning, may lead to decreased QoL in elderly people newly diagnosed with cancer.

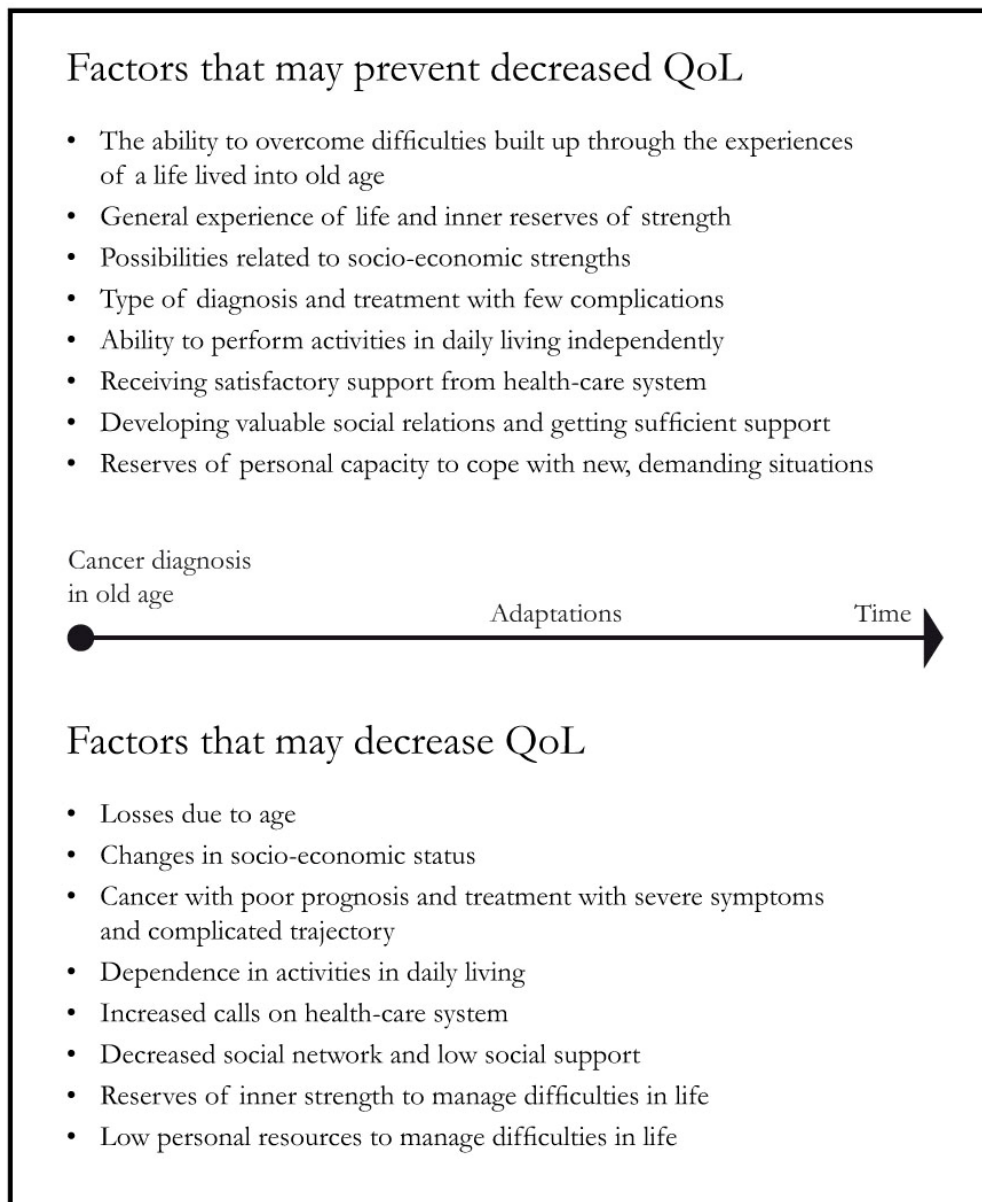


Figure 1. Factors with significant influence on quality of life of elderly persons with newly diagnosed cancer

Quality of life

Quality of life is a critically important concept that has been developed for health care, predominantly in the past three decades (Ferrans, 1996). There has been increasing focus on the assessment of patients' QoL (Repetto et al., 2001) and the concept of QoL is extensively used (Ganz and Reuben, 2000). However, there is no consensus about the definition of QoL (Bowling, 1997), and how it should be measured, although plenty of tools are available. Disagreements exist to what domains should be emphasized in definition of QoL (Bowling, 2001). QoL is defined by WHO (1993, p. 1405) '*Individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships and their relationship to salient features of their environment*'. This definition takes individual perception and relationship to the environment into account (Bowling, 2001), and furthermore see, QoL in a cultural, social and environmental context. QoL covers a broad conceptualisation that emphasises both a subjective and an objective approach, the *multidimensional evaluation by both intra personal and social-normative criteria of the person-environment system of an individual in the time past, current and anticipated* (Lawton, 1991, p. 6).

The dimensions of QoL can be described in four major aspects: Behavioural competence, perceived QoL, objective environment, and psychological well-being. Each of these sectors can consecutively be described in minor 'sub-dimensions'. The four sectors are closely connected with each other and the content in each sector partially overlaps the others. Behavioural competence is described as the social normative evaluation of a person's functioning in the health, cognitive, time-use and social dimensions (Lawton, 1991). Perceived QoL is central to all approaches in QoL. Behavioural competence and perceived QoL are the central aspects of QoL, and objective environment and psychological well-being can be seen as essentially complementary to a holistic view of QoL (Lawton, 1991). Basically, QoL as a concept represents individual responses to the physical, mental and social effects of illness on QoL and influence the extent to which personal satisfaction with the circumstances of life can be achieved (Bowling, 1997).

Quality of life and old age

It is well documented that to experience 'control' in life is important for the individual's QoL. 'Late life' is characterised by accumulation of events that cannot be controlled as e.g. loss of health and social contacts (Atchley, 1997). However, late life is more than that. It is also characterised by new possibilities such as leisure, and development of pre-existing social relations or establishment of new relations (Atchley, 1997). The majority of people have an understanding of what a 'good life' involves: they take it to be a condition of harmony, and one where fundamental wishes and needs are met. These wishes and needs will vary from person to person. At the same time, most people have perceptions about old age, and expectations to which factors contribute to make old age 'good'. It is not sufficient to obtain QoL in one's life, it is important also to retain it. In other words, QoL must be viewed as a dynamic process. In a qualitative study (aged 80+; n=11) the meaning of home, how life was viewed, thoughts about dying and death proved to be areas of importance for perception of QoL among the elderly. An elderly person's ability to adjust

to life in the face of changes and new conditions and meaning in existence stood out as the core of QoL (Borglin, 2005).

Studies among elderly persons have verified areas of special importance for QoL. In an interview study (65+) Farquhar (1995) found that social contact, well-being/good health, access to meaningful activities, family and a satisfactory financial situation were factors of positive effect on QoL. Health related complaints such as pain, fatigue and mobility impairment was found to predict significantly low overall and health related QoL in a Swedish study (aged 75-99; n=469) (Borglin et al., 2005). In addition, women reported a significantly lower QoL, and a higher degree of self-reported health complaints, than men (Borglin et al., 2005). Another study by Jakobsson (2004) (aged 75-102; n=532) showed that financial problems, living in sheltered housing and living alone were associated with low QoL among those in pain. From the above mentioned studies, areas of special importance for QoL in elderly persons were social relations, help and support, mobility, having enough money for basic needs and remaining independent. As elderly people are more often exposed to loss, bereavement and illness, psychological emotional complaints should also be taken into consideration when measuring their QoL (Achat et al., 1998). Considering QoL to be a multidimensional concept, it may vary over time especially in elderly, where a number of changes occur simply due to being elderly. Understanding of QoL and changes over time in the elderly may be of particular importance in enhancing the support they may need.

Quality of life and cancer

In relation to introducing new principles within cancer treatment, the medical debate surrounding QoL increased within the medical world at the end of 1970s. Treatments were often experimental and had a number of side effects. In the same period, the biomedical understanding of cancer started to change. In the beginning of the 70s and 80s, the relation between cancer and psyche, and bio-psycho-social reactions on cancer started to be explored. The effects of the new types of treatment were very limited, and many health-care professionals asked themselves if the limited effect was able to compensate for the many negative side effects, and in which way the 'non-biological' part of a person's life was affected by the treatment (Forchammer, 1999).

To identify the influence of prognostic factors on psychosocial status and Health Related Quality of Life (HRQoL) in patients with breast cancer a prospective study was performed (Goodwin et al., 2004). In total, 397 patients with different stages were included in the study; the mean age was 52 years (SD 9.9). HRQoL and psychosocial variables were identified to have important association with survival in women newly diagnosed with cancer. King (2000) investigated QoL in persons with breast cancer three and 12 months after surgery (n=305 at three month and n=291 at follow-up) in relation to treatment and patient characteristics, and found that younger women fared worse than older women on a broad range of QoL dimensions. Single women and those with less education fared worse on a number of QoL dimensions, while age became an influential covariate. The results indicate the importance of patients' characteristics to QoL and to the treatment to be chosen (King et al., 2000). QoL in persons with colorectal cancer (mean age 70, SD 12, range 19-90; n=86) were investigated from time of diagnosis following five to eight months after surgery. Significant improvement in QoL was found

in emotional functioning, as well as appetite and global QoL (EORTC), and increased financial impact (Ulander et al., 1997). Lower mean score in global QoL was found pre-operatively and at follow-up for patients who were dependent in ADL compared to them who were independent in ADL (Ulander et al., 1997). Another follow-up study followed persons with gynaecological cancer (age: 18-75; n=173) 5 weeks, 3, 6, 12 and 24 months after surgery in relation to QoL (EORTC). It was found that over time, the patients adapted well to the morbidity after radical hysterectomy. Radiotherapy had a severe negative impact on the patient's sexual life in those with advanced cancer (Jensen et al., 2004). The early stage was found to be associated with short-term negative impacts on patients' physical, emotional, social, cognitive and role functions (Jensen et al., 2004). Montazeri (2003) investigated patients within newly diagnosed lung cancer (mean age 67.5, SD 9.1; n=129 at baseline, and n=82 three-months after) and how QoL changed with the first three months. Over time, sleep difficulties improved slightly and health related problems increased. In addition, patients functioning and global QoL (EORTC) decreased within this period. QoL in persons with lung cancer is not limited to physical functioning, but also to other symptoms, which result for either progression of the disease or side-effects from treatment. Comprehensive assessment of physical symptoms as well as physical functioning and psychosocial well-being are suggested in evaluation of persons with lung cancer (Montazeri et al., 2003). None of these studies focused especially on elderly with cancer. Though, the results indicate that QoL is affected in various ways regarding age, socio-economic conditions, ADL-function, psycho-social issues, health-related problems and symptom complaints. However, knowledge is needed about how these factors are related to QoL in the elderly with cancer.

Quality of life in elderly persons with cancer

Improvement and maintenance of QoL are a major goal of medical care, especially in conditions in which the improvement of survival is limited and is paid at the price of significant complications (Overcash and Balducci, 2003). This issue is particularly relevant to the aged person with cancer, who has a limited life expectancy and increased risk of complications from their treatment (Overcash and Balducci, 2003). However, there has been very little research in respect of QoL in the elderly with cancer and what has been done is mostly restricted to specific treatments.

QoL assessment is widely accepted as part of the assessment of outcomes during clinical trials of new cancer treatments (Albert, 2000). Although the majority of persons with cancer are aged over 65, the elderly are not always adequately represented in QoL research (Ganz, 2004). Thome et al, (2004) found that receiving help for daily living from others and degree of complaints were associated with poor QoL in old cancer patients (aged 75+; n=150). In another study, women were identified as more vulnerable than their male counter partners in QoL in regard to their perceived financial situation and social resources (Thomé and Hallberg, 2004). QoL studies in the elderly with cancer should be carried out with the aim of improving understanding of their values and estimation of QoL, especially over time.

Assessment of quality of life

Choosing an instrument to measure QoL (generic or HRQoL) is dependent on the research question (Rustoen et al., 1999). Several aspects may have an impact on QoL in elderly persons with cancer. Farquhar (1995) interviewed elderly people (age 65+; n=210); about which factors describe QoL, and found that social contacts, health and mobility were revealed as central factors for good QoL. Helplessness, disability, poor health, old age and reduced social contacts were factors reported to be related to poor QoL (Farquhar, 1995). According to Birren and Dieckmann (1991) physical health, physical functioning, psychological functioning, social functioning, cognitive functioning, economical status, environment, health perceptions, life satisfaction, self-esteem, sense of control, autonomy and choice should be domains included in QoL as measured among elderly persons. Nevertheless, knowledge based on HRQoL contributes to bridging the gap of understanding, and can provide significant understanding about the specific needs of the elderly with cancer.

Ranges of standardized questionnaires have been developed for measuring QoL. Generally, QoL instruments are divided into two groups, generic and disease-specific ones. Generic QoL instruments are designed to be applicable across all diseases and conditions across different medical interventions and across a wide range of populations (Bowling, 2001, Harrison et al., 1996). Generic instruments also have an impact constraint as they are unable to identify the condition-specific aspects of a disease that are essential for the measurement of outcome (Bowling, 2001).

EORTC QLQ-C30, developed by EORTC (European Organization for Research and Treatment of Cancer), is one of the most frequent HRQoL used instruments within the cancer field in Europe. In the 1980s, a Study Group on Quality of Life was created within the EORTC, which in 1986 initiated a research programme to develop an integrated, modular approach for evaluating the QoL of patients participating in cancer clinical trials (Fayers et al., 2001). The model of QoL is multidimensional, and the authors explicitly define QoL in relation to the defined core elements of functional status, cancer and treatment-specific symptoms, psychological distress, social interaction, financial/economic impact, perceived health status and overall QoL (Bowling, 2001, Fayers et al., 2001). The EORTC scale has been widely used, not only in European settings but also in Asia due to its strength across different cultures. EORTC's model appears to reflect changes over time, and differences between treatment groups and type of cancer, though it has been criticized as being too narrow and to ignore much of the impact of cancer on social life. The sensitivity of EORTC for use with elderly persons with multiple pathology has scarcely been assessed (Bowling, 2001). However, in view of these gaps, the EORTC group has recently appointed a task force group to develop the instrument to address specific problems related to the elderly.

Activities of daily living

Aging is a process of diminishing functional reserves, and cancer seems to tests the reserves of an elderly person (Garman and Cohen, 2002). Furthermore, old age seems to be a gradual process of determining in which way getting cancer affects the functional ability;

the ability to manage daily living may be of particular concern. Activities of daily living (ADL) concern the ability to manage daily life independently (Hulter Åsberg, 1998). ADL as a concept can be assessed at two levels: Personal ADL (PADL) and Instrumental (IADL). IADL measure a person's ability to maintain an independent household (e.g. shopping for groceries, driving or using public transport, using the telephone, meal preparation, housework, laundry, taking medications, and handling finances) (Ganz and Reuben, 2000). PADL assess the ability of a person to complete basic self-care tasks (e.g. bathing, dressing, toileting, continence, feeding and transferring) (Ganz and Reuben, 2000).

During the last couple of decades, several studies have described large variations in patterns of change in functional ability and have proved that QoL among elderly people is highly affected by dependency in ADL following reduced functional ability (Avlund et al., 2004). A study by Hellström (2004) among old people (age 75+, n=1247), receiving help in ADL, showed that a high level of help, more than other factors such as type of housing and age, in PADL particularly affected QoL negatively (Hellstrom et al., 2004). The ADL function of the elderly with cancer has also been studied. Given (2001) found that newly diagnosed patients with cancer aged ≥ 65 had levels of physical functioning comparable to men and women aged 55-64 years. Further, Given found that physical functioning declined in substantial numbers of patients after treatment began. Courtens (1996) found in 52 newly diagnosed cancer patients (followed during the first year) that patients who had reduced functioning, had a greater need for instrumental support. In another study patients newly diagnosed with cancer (aged 65+; n=907) tended to start with a decreased level of physical function at the time of initial cancer diagnosis and then regained some function over the year following diagnosis (Given et al., 2000). Given found that there were differences of effect on function based on cancer type, (e.g. lung cancer patients had the lowest level of physical function) and type of treatment type n (patients receiving chemotherapy reported lower levels of physical functioning than did patients who were not receiving chemotherapy). Goodwin (1991) assessed the functional status and social support networks in the elderly newly diagnosed with cancer (aged 65+; n=799). The percentage of patients with functional limitations increased sharply with increasing age, and participants with dependency in ADL were more likely to have poor social support networks than participants without such limitations. Research is needed to demonstrate patterns of dependency in ADL as well as the impact of dependency on QoL in the elderly with cancer. Dependency is often depicted as different degrees of functional limitation, but it may also include psychological limitations (Flanagan and Holmes, 1999). Questions persist about how ADL may change over time once the diagnosis of cancer is made and how the related QoL responds to those changes. Such knowledge is needed to plan services and integrate the support provided.

The increasing incidence of cancer among the elderly, and the need to understand their functional status point to the need for assessment of activities in daily living in elderly with cancer (Garman and Cohen, 2002, Goodwin and Coleman, 2003). Fortunately, the importance of functional status has been recognized by oncologists for decades and has been used to provide prognostic information (Ganz and Reuben, 2000). Though the individual's performance in PADL and IADL can be studied in different ways: through self-reports (in an interview or a questionnaire), estimation by the persons himself/herself, observation by an external examiner of what the person actually does, or testing the

persons' ability to perform different tasks (Hulter Åsberg, 1998). Some measures focus simply on basic functioning (e.g. mobility) but, more commonly, they include items of instrumental, or extended, activities of daily living, which encompass the activities that are required for the maintenance of independence, as well as optimum levels of functioning (e.g. doing laundry, housework, preparing meals) (Bowling, 1997).

Most scales have been developed by professionals, such as medical doctors, in order to systematise judgements about essential abilities for daily living. The problem of measuring functional disability is compounded by conceptual difficulties and interactive factors (Bowling and Grundy, 1997). One of the major problems with using a functional index is that different people may react differently to apparently similar levels of physical impairment, depending on their expectations, priorities, goals, social-support networks and so on (Bowling, 1997). In many respects, a person's ability to function in daily living is among the most important measures of the overall impact of his or her diseases and/or disorders. From a clinical perspective, the major shift for health care professionals is to measure not only ADL for prognosis or outcome purposes, but to attempt also to remediate dependency as part of the management plan (Ganz and Reuben, 2000).

Social network and support

It is well-known that serious illness of any kind increases the need for closeness to competent people to counteract the feelings of insecurity and vulnerability (Rowland, 1990, Weisman, 1976). Since the experience of cancer represents a particularly stressful situation, the role of social support as a buffering factor is obvious (Lalos and Eisemann, 1999, Stafford and Cyr, 1997). A cancer diagnosis elicits adaptation demands that, though perhaps not unique to persons with cancer, may make the patient especially dependent on social supports (Rowland, 1990). During illness people tend to feel less in control, less powerful and more inferior, especially when they cannot help themselves and must rely on others (Stamnes, 2000). Elderly persons diagnosed with cancer may be especially vulnerable due to a diminished social network and support, which can lead to social isolation (Luggen, 1999).

Social network is a concept acquired from anthropological studies (Ell, 1984), and as a concept social network and support has been studied extensively during the past decades (Hinde, 1987, Hinde, 1979, Hupcey and Morse, 1997, Ryan and Austin, 1989, Unden, 1991). Though, theoretical definitions of social support remain vague, that anything associated with support of factors that may influence whether support is requested, given, or accepted have been clustered under, and labelled as, social support (Ell, 1984). According to Ell (1984) the purpose of social support is to affirm personal identity, enhance self esteem, and expand coping skills (Ell, 1984). Due (1999) have described *social network* as the structural element of the description of interactions within social relations (including elements such as density, dispersion, duration). In contrast, *social support* has been described as the functional aspect of social relationships, and consists of four categories: informational, instrumental, emotional and appraisal support (Due et al., 1999). Seen another way, social network contain two dimensions: structure and function. The *structure* refers to the type of individuals in the social network and the frequency of contacts between these individuals. The structure cover two dimensions: formal relations

(includes professionals and acquaintances) and informal social relations. The *function* of the social network is comparable to the social support concept, and thus covers the qualitative and behavioural aspects of the social network (Due et al., 1999).

There is considerable evidence that persons with strong social relationships have increased resistance to disease and lower morbidity and mortality (Due et al., 1999). Lack of social ties to others has been shown to be a significant risk factor for psychological well-being, happiness, illness and death (Stamnes, 2000) and social ties seem to provide a better possibility of recovery or survival after illness (Due et al., 1999). However, a social network may not always be perceived as a resource of benefit (Krishnasamy, 1996). Persons who are physically ill, and especially those with cancer, may find that their social relationships not only fail to buffer them from the stress of the illness, but actually constitute an additional source of distress (Due et al., 1999). It is important to be aware that social network and support can seem confining or be experienced as a conflict. For others social support can reduce autonomy, which in turn reduces QoL (Stamnes, 2000). However, Bowling and Farquhar (1995) investigated elderly persons (aged 85+, n=630 at baseline, and n=464 2.5-3 years after) and reported that networks do respond to the needs of the elderly. However, the greater is the loss of relatives the greater are the consequences, given that the relatives provided practical help (Bowling and Farquhar, 1995).

Cancer in the elderly and the benefits of social network and support has hardly been investigated. Rustoen (1999) found in newly diagnosed cancer patients (aged 19-78; median age 52; n=131) that the younger group (19-39 years) living alone had significantly lower quality of life than the elderly group living alone (60-78 years). Although age was significantly associated with quality of life in only one sub-scale, the elderly people reported their quality of life to be better in almost all sub-scales (Rustoen et al., 1999). There is considerable research evidence that elderly cancer patients suffer fewer negative psychosocial consequences than do younger patients. Various explanations have been proposed. Mor et al, (1994) argued that elderly individuals may cope better because they have fewer competing demands such as jobs or children in their lives. However, it is obvious that life-long experiences may add to the capacity of the elderly to manage different situations despite changes in social network and support.

The aging process can be accompanied by retirement, financial worries, and changes in living arrangements and bereavement through loss of spouse, other family members, or friends (Kane, 1991). All of these changes or losses pose threats to the patient's social support system (Roberts, 2004). Although a correlation between advancing age and better psychosocial adaptation to cancer has been demonstrated, the relationship between the two variables is not a strong one (Ganz and Reuben, 2000). The quality of social support available may also vary over time. Over the course of illness, there may be peak demand periods for additional social support for and other specific types of support. Just as the person's needs and demands may vary over time, so do his or her support network (Roberts, 2004).

The health-care system as the formal input has been emphasised as an important type of support (Roberts, 2004). However, according to Hupcey and Morse (1997) there is a major difference between social support and professional support. The unique aspect of social support is that the action must be given by someone who has a personal relationship

with the recipient. Professionals may provide support to an individual but that is not social support, which has unique characteristics different from those of professional support (Hupcey and Morse, 1997). Most of these specific characteristics of social support are based on the nature of the relationship. The relation between a professional and a patient is influenced by certain role expectations (Wells and Balducci, 1997). This issue may be of importance for investigating elderly cancer patients, since most of them are in contact with the health care system, regarding both possible cancer treatment and help in daily living.

According to Bowling (1997) measuring social network and support is fraught with difficulties, as most measures have not been fully tested for validity and reliability, but need to be so tested and at least have well-defined concepts. Objective measures attempt to quantify an individual's social interactions by assessing size, density and other characteristics of social networks. Objective definitions of social network could include reliance on relatives, frequency of contact with friends or family, or memberships of social organisations such as neighbourhood groups. Uden (1991) emphasises that to choose an instrument it is important to differentiate between two main dimensions of social support: Close emotional ties (attachment) on the one hand, and relationships to friends, neighbours, family members (social integration) on the other (Uden, 1991).

Since social network and support seems to be significant to the elderly with cancer, more research may be needed to understand how social network and support influences the elderly and their QoL, and to understand how they sustain the support that can be obtained from their social network. Very few studies have specifically examined the social network and support experienced by elderly persons with cancer. Questions persist about what influences the patient's social network and support, how it is experienced over time once the diagnosis of cancer is made and the impact on QoL. More detailed information about cancer in the elderly and social network is needed to plan services and integrate support provided (Goodwin et al., 1991, Repetto et al., 1998).

Hope

Hope may be related to survival and strength, and is particularly important for people diagnosed with a life-threatening illness (Benzein and Saveman, 1998), such as cancer. People newly diagnosed with cancer are in a specially vulnerable and unknown situation whereby cancer can threaten hope and make the future uncertain. In addition, the elderly with cancer may face the inevitable reality that life expectancy is limited due to disease and old age. However, hope in the elderly with cancer and its influence on QoL may be of importance and in improving their ability to manage the situation.

Over the past decade the importance and the meaning of life in those living with cancer has been increasingly described in the literature (Ballard et al., 1997, Halldorsdottir and Hamrin, 1996, Rustoen, 1995, Smith and Stullenbarger, 1995). Also the importance of hope, and meaning and how to maintain and measure hope has been of interests within cancer care (Hinds, 1984, Nowotny, 1989, Rustoen, 1995, Rustoen and Hanestad, 1998, Rustoen and Wiklund, 2000). Although the concept of hope has been discussed, no consensus on a common definition has been obtained. Seemingly the agreement on hope

converges on it as an inner power (Herth, 1990), a multidimensional dynamic and process-oriented life force (Dufault and Martocchio, 1985, Nowotny, 1989), anticipation of a future which is good and based upon mutuality (Cutcliffe and Herth, 2002, Nowotny, 1989). Nowotny (1989) also included involvement by the individual coming from within the person.

Hope has been defined, as a catalyst that assist individuals to cope successfully with life challenges and transitions to facilitate continued functioning during chronic illness and other significant possible multiple losses (Farran et al., 1995, Forbes, 1999, Raleigh, 1992). This is especially important in the view of elderly persons to be challenged with the task of maintaining hope in the face of loss (Herth and Cutcliffe, 2002). Defining hope in relation to achievement, success, and control is problematic for elderly persons who may experience a loss of their spouse and friends, movements from the family home, and/or reduction of physical capacity (Farran et al., 1995, Herth, 1990). Assuming hope to be a catalyst to assist persons to cope successfully with changes in life, and to be an inner power of a person, it should be independent of losses and absence of success. Instead, hope may be based in a person's ability to maintain hope itself in a particular situation, despite losses and difficulties.

Few studies report on hope and QoL in cancer patients or in elderly people. Nevertheless, Rustoen (1998) observed in an intervention study (age range 26-78; n=96 newly diagnosed cancer patients) that hope scores in 'the hope group' were significantly improved two weeks after the intervention compared with the two different control groups (Rustoen and Hanestad, 1998). According to Rustoen (1998) one problem in employment of the two concepts 'hope' and QoL is that they can be seen as two separate concepts. Although the concepts are dependent on one another, the relationship is not simple. Though earlier intervention studies have explained a relation between hope and QoL, and that both improve following intervention (Herth and Cutcliffe, 2002, Herth and Cutcliffe, 2002, Rustoen and Hanestad, 1998). Nowotny (1989) identified hope as an important factor in QoL of individuals with cancer (age 20-80 years; n=150). She also found that hope was present in all aspects of life and that it could change over time, as difficult situations evolved. Thus, hope may buffer against decreased QoL and be regarded as a personal resource.

Few studies describe hope in relation to that population of people who are both elderly and have cancer (Duggleby and Wright, 2004, Duggleby and Wright, 2005). Dufault et al, (1985) identified six dimensions from interviews with 35 elderly patients with cancer, and identified several threats that were similar to those in a sample of the patients who were critically ill. These threats included evidence of psychical deterioration; behaviour of family, physician, nurses. A Swedish qualitative study identified loss of hope to be threatening to an elderly person with cancer, as it represents a strong reminder that life is limited (Thomé et al., 2004). However, McGill (1993) found that age (age range from 65-86 years) was not significantly related to hope. Instead, lower socio-economic status and declining physical health were identified to be threats to hope. According to Nowotny (1991) the time aspect may not necessarily be important because seriously ill persons especially speculate less on cure or extra years of life but rather on what is possible and realistic in the situation (Nowotny, 1991). This is in line with Benzein (1998) who identified hope of healthy persons as a process linked to meaning of life. Hope was also

identified as a fundamental will to engage in living life, and was linked to a positive attitude to life. Therefore, hope is a notion that not only contains the number of years to live, but also the *meaning* of life, which is in line with the findings of Nowotny (1991).

Although hope is fundamental for human beings, it is seldom included neither in the definition of QoL, nor in the instruments that measure it (Rustoen and Hanestad, 1998). Scales measuring hope have been developed (Herth, 1992, Miller and Powers, 1988, Nowotny, 1989), though are not targeted especially for elderly cancer patients. Establishing content validity for any hope instrument is challenging because the nature of hope is multidimensional. Many instruments that measure hope are prospective or future-oriented in its nature (Grann, 2000). Some instruments attempt to measure all domains within the multidimensional construct (Herth and Cutcliffe, 2002, Herth and Cutcliffe, 2002), whereas others focus on one domain (Grann, 2000). Hope in persons with cancer may not always be in line with the patient's experience, since cancer patients may have their own reality which can be quite different from that of those around them (Owen, 1989, Yates, 1993). This underlines the necessity to explore the perspective of elderly persons with cancer and their experience around existential issues such as cancer.

In summary, the number of elderly persons with cancer is increasing because of the expanding number of elderly persons in the Western world, and the high and still increasing incidence of cancer in this group. It means that health care professionals face the challenge of providing increasing amounts of quality care to patients who have unique care requirements. QoL is known to be an important outcome variable within health care due to disease, treatment and ability to manage daily living with a cancer diagnosis. Getting cancer as an elderly person implies an illness trajectory where one's life condition changes over time. To contribute to the base of knowledge about elderly persons with cancer, this thesis focuses on their QoL and areas of intervention to improve it. To do so multiple methods are applied. It means that two different research methods were conducted, because different perspectives enable better achievement of the aims (Morse, 2003). Several possible associated factors must be considered. These factors should not be studied in isolation in relation to the elderly with cancer and QoL, because the interrelationships with QoL in the elderly with cancer vary in degree as with each other from person to person. These factors may be associated with QoL in the elderly with cancer, and are activities of daily living, social network and support, hope, socio-economic condition and contact with health-care system. The lived experience of getting cancer in old age is necessary because the subjective perspective particularly may contribute to valuable insight in elderly people's life world. Knowledge about elderly persons with cancer increases the possibilities of improving their quality of care and QoL.

AIMS

The overall aim of this thesis was to investigate the quality of life of elderly persons from time of a cancer diagnosis through the following six months. The aim was further to investigate changes in quality of life over time in relation to type of cancer, age, socio-economic conditions, ability to perform activities of daily living, contact with health-care system, social network and support, and hope. Moreover, the aim was to illuminate the lived experience of getting cancer in old age.

The specific aims were:

- To investigate the QoL of persons newly diagnosed with cancer (65 years and above) in relation to age, contact with the health-care system, ADL, hope, social network and social support, and to identify which factors were associated with low QoL (Paper I)
- To investigate QoL in persons aged 65 years and older diagnosed with cancer three months from time of diagnosis. The study also aimed to investigate ADL, hope, social network and support and their relationship to low QoL at three months after diagnosis (Paper II).
- To investigate possible changes in QoL in elderly persons aged 65+ diagnosed with cancer three and six months after diagnosis regarding: ADL, hope, social network and support. The study also aimed to investigate which of these factors could predict deteriorated QoL in elderly persons with cancer from baseline to six months after diagnosis, and to explore further those persons with stable versus deteriorated QoL (Paper III).
- To illuminate the lived experience of getting cancer in old age (Paper IV).

MATERIAL AND METHODS

Design

The use of multiple methods contributes to understanding the complexity of human experience (Morse, 2003), which in this thesis is elderly persons newly diagnosed with cancer and through the following six months. Using multiple methods means to apply two or more research methods (Morse, 2003). All methods have limits, and mixing different types of methods may strengthen the understanding of the complexity of elderly persons with cancer. The multimethod component design was that quantitative and qualitative methods were combined.

The quantitative data in this thesis were obtained in a prospective follow-up study design. Prospective follow-up designs are appropriate for studying a sample with common characteristics and quantifiable variables over time (Polit and Hungler, 1999), which in this thesis meant three interviews with the same group at an interval of six months. A comparative design was used to compare QoL in different age groups (Paper I), and to compare QoL on group level between baseline, three-month follow-up and six-month follow-up (Paper II-III). A correlational design was used to investigate factors associated with low QoL (Paper I-II) and those predicting deteriorated QoL (Paper III). The strength of this method is that not only can a specific situation be assessed, but changes in people's views upon a specific situation or condition can be obtained (Bowling, 2002), and used to identify risk predictors of a specific course (Kazdin, 2003). Difficulties in method occur if there is high sample attrition through natural loss particularly death (Bowling, 2002). In addition, follow-up studies are time consuming, and costly in terms of personal resources (Kazdin, 2003). The qualitative part of this thesis was a phenomenological study, aimed to investigate the lived experience on an individual level of getting cancer in old age (Paper IV). Qualitative interviews were analysed with the phenomenological method (Giorgi). Life world research aims at illuminating the subjective experience of a phenomenon with the thoughts, feelings and attitudes it creates in a person (Dahlberg et al., 2001), and requires that the researcher become heavily involved for a period (Morse and Richards, 2002).

The quantitative and qualitative methods allows the researcher to use both numbers and words and, though, these methods belongs traditionally to different paradigms with fundamentally different epistemological framework (Foss and Ellefsen, 2002). Both studies are complete in themselves and answer a particular sub-question with a deductive theoretical drive. The multiple method design was chosen to broaden insight into the elderly with cancer, and to obtain a more complete picture of the situation and the patient's experience of being diagnosed with cancer. The aim of this thesis has decided the choice of methods, which was both to assess QoL over time and to understand the lived experience of getting cancer in old age.

Sample

The baseline sample consisted of 101 elderly persons (age 65+ years), consisting of 76 women and 25 men, newly diagnosed with cancer included in the follow-up study (Paper I-III). The median age of the participants in the baseline sample was 74.74 years (IQR 8.75), ranging from 65 to 97 (Table 1). Over a period of five months, 280 potential participants referred to the oncology clinic, of whom 160 died and 120 were asked to participate in the study. In total, 31 refused to participate, due to general frailty (n=10), cognitive dysfunction (n=4), next of kin not wanting them to participate (n=10), or for unspecified reasons (n=9) (Figure 2). All participants had to have been referred to the Department of Oncology and to have been newly diagnosed with cancer, which meant diagnosed within the previous two to three weeks. They should be receiving cancer treatment or supportive hospital care. Furthermore, they should be Danish speaking, be mentally well-functioning and be informed about their cancer diagnosis. The inclusion criteria were moreover persons aged 65+ years belonging to one of four different diagnosis groups: Breast (n=24), Colorectal (n=26), Gynaecological (n=25) and Lung (n=26) cancer. The four diagnosis groups were chosen pragmatically because of their prevalence and with the expectation of obtaining a reasonably coherent sample to analyze by limiting the number of diagnoses in the study. The exclusion criteria were cognitive dysfunction or general weakness. Concurrent non-malignant disease was not an exclusion criterion.

The sample in Paper IV consisted of 16 elderly (aged 65+) persons (12 women and 4 men) who had been diagnosed within a period of 2-8 months, and who were willing to participate and share their experience of living with cancer in old age. The median age was 73.90 (IQR 5.19), range 68-83. All participants were selected from the follow-up study. In total, 35 participants were selected, and were recruited in relation to high global QoL or low global QoL (eight of each) to obtain maximum variation (Mayan, 2001, Speziale and Carpenter, 2003). Nine of the 35 had died, and 26 participants were contacted by the author by telephone inquiring if they wanted to participate in this specific study. Ten persons did not want to participate in further interviews, because they had already participated in the follow-up study, frailness, next of kin not wanting their relative to participate in further studies, or other reasons for unwillingness. All participants were admitted to an out-patient oncology clinic at a hospital in the County of Copenhagen, Denmark. The participants were four from each of the same diagnosis groups as above (Breast, Colorectal, Gynaecological, and Lung cancer). To be eligible for this part of the study, participants should be receiving supportive hospital care or cancer treatment, be Danish speaking, lucid, and fully informed of their cancer diagnosis. Competitive non-malignant diseases were not an obstacle to participation. Altogether, 11 participants lived with their spouse, one lived with a daughter, and four lived on their own.

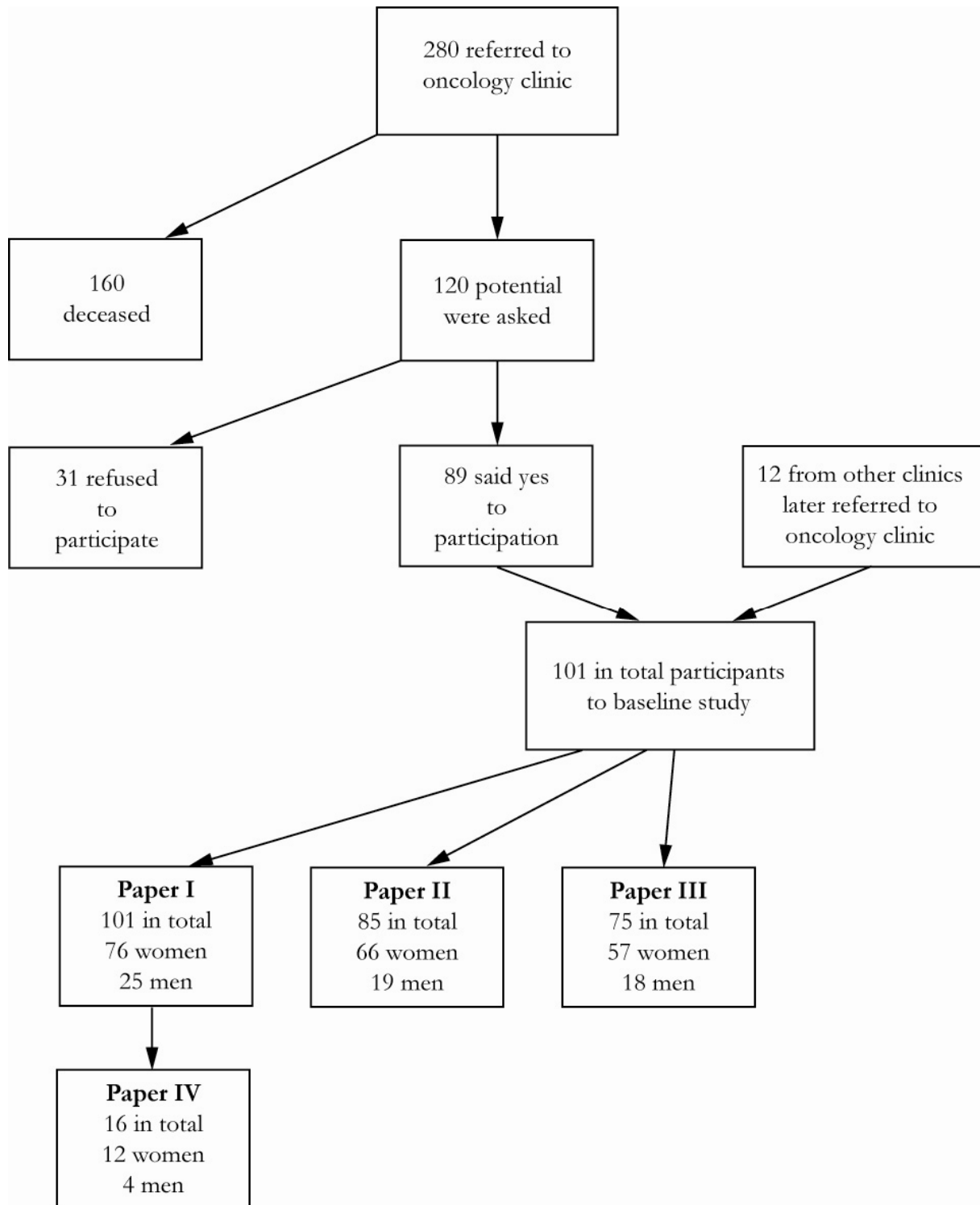


Figure 2. Overview of the samples in Paper I-IV

Table 1. Characteristic of the participants in the studies

	Paper I	Paper II	Paper III	Paper IV
Number of participants included	101	85	75	16
Age, median (IQR)	74.74 (8.75)	75.48 (8.35)	75.49 (8.7)	73.90 (5.19)
Sex, %				
Male/Female	26.7/73.3	24.7/75.3	24.0/76.0	25.0/75.0
Marital status, %				
Married/Not-married	50.5/49.5	49.4/50.6	46.7/53.3	68.8/31.3
Accommodation, %				
Apartment	44.6	41.2	41.3	18.8
House	52.5	55.3	56.0	81.3
Sheltered accommodation	3.0	3.5	2.7	0
Years at school, median (IQR)	8.00 (3.00)	8.00 (3.00)	9.00 (3.00)	10.00 (2.75)
Last profession/occupation, %				
Housewife or blue-collar worker	46.5	44.7	44.0	43.8
Employee/civil servant	33.7	34.1	34.1	37.5
Self-employed	19.8	21.2	21.3	18.8
Diagnoses, %				
Breast cancer	23.8	28.2	30.7	25.0
Gynecological cancer	24.8	24.7	25.3	25.0
Lung cancer	26.7	21.2	17.3	25.0
Colorectal cancer	24.8	25.9	26.7	25.0
Treatment, %				
Surgery	66.3	69.4	72.0	62.2
Chemotherapy	38.6	40.0	38.7	56.3
Radiation	53.5	50.6	52.0	37.5

Calculation of the necessary sample size in follow-up studies, with allowance for a drop-out rate of 25% between baseline and follow-up at three months, showed that inclusion of 100 patients at baseline would give a power of 93% to detect a clinically relevant difference of 10 units in the EORTC QLQ-C30 from baseline to three months.

Not participating at three- and six-month follow-up

‘Not participating’ refers to participants who were included and/or took part in the baseline study, but were lost during the three and/or six-months of the follow-up studies. Sixteen persons (10 women and 6 men) did not participate at the 3-month follow-up (Paper II). In total, 26 persons (17 women, 9 men) who participated in the baseline study were the non-participants six months later (Paper III) (Table 2).

Table 2. Characteristic of those not participating at three- and six-month follow-up

Numbers not participating	Paper II (n=16)	Paper III (n=26)
Reasons for not participating	14 deceased, 1 frail, 1 psychotic	25 deceased, 1 frail
Age, median (IQR)	71.62 (12.03)	73.90 (9.88)
Sex, %		
Female/Male	62.5/37.5	65.4/34.6
Marital status, %		
Married/Not married	56.3/43.8	57.1/35.7
Accommodation, %		
Apartment	62.5	50.0
House	37.5	39.3
Sheltered accommodation	-	3.6
Years at school, median (IQR)	7.00 (3.00)	7.50 (3.00)
Last profession/occupation, %		
Housewife or blue-collar worker	56.3	50.0
Employee/civil servant	31.3	28.6
Self-employed	12.5	14.3
Diagnoses, %		
Breast cancer	-	3.6
Gynecological cancer	25.0	21.4
Lung cancer	56.3	50.0
Colorectal cancer	18.8	17.9
Treatment, %		
Surgery	50.0	46.4
Chemotherapy	31.3	35.7
Radiotherapy	68.8	53.6

Health Care Context

The participants in Paper I-IV were referred to the same oncology outpatient clinic in Copenhagen County. Some of the participants came from other clinics (medical or surgery), primarily from the same county. The participants had gone either through a surgical procedure or through an examination programme to verify the diagnosis before being referred to the oncology outpatient clinic. All participants belonged to a diagnosis group at the outpatient clinic, and were primarily met by the same team of nurses. However, that was not necessarily the case when meeting the physician. There were no special routines regarding the participants being elderly, though the nursing team strove to oblige them with individual needs. In addition to the outpatient clinic setting, some were also during the study period in hospital. However, some were also in contact with the primary health-care system or other clinics such as e.g. ostomy care, chest departments, and departments of urology and gynaecology. In Denmark, all citizens have access to the health-care system irrespective of their financial situation. The oncology

outpatient clinic that the participants were referred to is a part of a university hospital and has specialist responsibility for a large geographical area. For the duration of this study the author was employed at the oncology clinic to perform it but was not involved in, and had no knowledge of the daily practice or routines, neither had she any influence on treatment or care provided.

Data collection

In the beginning, as part of a pilot test (test of the interview schedule and the interview procedure before carrying out the main study), participants (12 in total) were asked by the Head Nurse in five different clinics to participate in the study. The pilot test showed the interview schedule to be feasible and only some minor amendments were made in the interview schedule for the main study. Coincidentally, it became obvious that this procedure was insufficient to recruit sufficient participants and the procedure changed. Though the 12 participants were all referred to the oncology clinic and entered the main study, further recruitment of participants was at random from a hospital reference list of the Department of Oncology, and participants were invited by a letter and subsequently contacted by the author.

The methods of data collection used in this thesis were both structured interviews based on a interview schedule (Paper I-III) and open-ended interviews (Paper IV). Because old age in some cases is characterised by losses of various kinds, special considerations were given when interviewing elderly persons. The author strove to be aware of possible 'problems' related to elderly persons that could interfere with the interview process such as sensory, physical and mental impairments (Wenger, 2002).

Structured interviews

The author conducted personal structured interviews from the study questionnaire; each taking 30-90 minutes. All consenting respondents participated in the interview at home; in hospital wards or outpatient clinics, or by telephone (Table 3). After being instructed by the author, two RNs were responsible for ten interviews each as baseline, and one RN was responsible for five interviews at three-month and six-month follow-up. The method (at patient's home, outpatients' clinic, telephone) used to perform the interviews was based on ethical and personal considerations, observing the situation and needs of the respondents. Substantial weight was given to the specific wishes of the participant in order to assure fewer missing data (Ganz, 2004) by minimizing internal and external drop-outs. No significant differences in QoL and/or changed QoL due to the different method used to collect the data were observed.

Table 3. Distribution of where data were collected

	At hospital	At home	By telephone
Baseline	n=59	n=23	n=19
Three-month follow-up	n=10	n=13	n=62
Six-month follow-up	n=5	n=13	n=57

To ensure homogeneous interview techniques, the author trained and instructed the oncology nurse involved. The quality of the interviews and the adherence to procedure and instructions were controlled systematically by the author through checking the filled-in questionnaires and by discussion. All data were reported in the interview, except from age, sex and type of cancer diagnosis. Participation involved an initial interview plus further interviews two; three and six months later. The structured interviews were performed during the period 2001-2002.

The interview schedule

The interview schedule consisted of four validated instruments about quality of life, activities of daily living, social network and support, and hope. The entire interview schedule (144 questions in total) used in Paper I–III was specifically composed for this study. The interview schedule contained also questions about socioeconomic data such as age, sex, civil status, housing, living conditions, education, economy and children and grandchildren. In addition, questions about type of disease and seriousness of the disease were raised such as ‘Has your doctor told you that the cancer disease is not over’. Additionally, questions about number of visits to the hospital and contact with the health-care system were raised. Variables on assistance were ‘Do you receive the assistance you need?’ and ‘Do you need any other kind of assistance, apart from the help you are presently receiving?’ and requiring help with ADL.

Assessment of quality of life

In this thesis the core interview schedule EORTC QLQ-C30 version 3 was used (Paper I–III) (Fayers and Bottomley, 2002). The European Organization Research and Treatment of Cancer (EORTC) ‘Quality of Life Study Group’ has developed the interview schedule for assessment of health related quality of life in cancer (Sprangers et al., 1993). A panel composed of members from various participating countries developed the core interview schedule (Anderson et al., 1993). The instrument was originally developed for cancer patients’ participating in international clinical trials, but it has also been used in different non-trial studies. The instrument is cancer specific (Carlsson and Hamrin, 1996), multidimensional and can be used in different cultures; designed for use across a range of cultural settings, and is translated into Danish (Anderson et al., 1993) The EORTC QLQ-C30 (version 3) consists of 30 items spread over three subscales. The functional scale incorporates five scales on physical function (PF), role function (RF), emotional (EF), cognitive (CF) and social functioning (SF). The symptom scale includes three scales on fatigue (FA), nausea/vomiting (NV), pain (PA), dyspnoea (DY), insomnia (SL),

appetite loss (AP), constipation (CO), diarrhoea (DI) and financial difficulties (FI). Questions are for example ‘During the last week, were you limited in doing either your work or other daily activities?’ The response format scores consist of a 4-point scale format ranging from one to four ‘not at all’, ‘a little’, ‘quite a bit’ and ‘very much’ (Fayers et al., 2001). The global health status/QoL consists of two questions on a seven-point scale ranging from one to seven. Subscale scores are linearly transformed to 0 to 100 grade scales according to Fayers (2001). A higher score for the functional subscale and global health status/QoL represents a better level of functioning, while a higher score on the symptom scales and single items indicates a greater degree of symptomatology.

The internal consistency of the instrument was calculated using Cronbach’s Alpha (Cronbach, 1951) and showed to be between $\alpha=0.77-0.94$, except for emotional function ($\alpha=0.65$) and cognitive function ($\alpha=0.45$) (Table 4). Despite EORTC-QLQ-C30 is being a cancer specific instrument, it has been used in populations studies with acceptable results (Hjermstad et al., 1998). Norm values for the general population are reported in several studies (Hjermstad et al., 1998, Klee et al., 1997, Michelson et al., 2000). The EORTC-QLQ (version 3) has been used for Swedish elderly persons and reached a satisfactory Cronbach’s Alpha ($\alpha=0.8$), except nausea and vomiting (NV) $\alpha=0.54$ (Thomé et al., 2003). The reliability test-retest was investigated in a Norwegian study the correlation was found high in all functions scales (0.82 for cognitive and 0.91 for physical function) (Hjermstad et al., 1995). Due to discriminant validity the strongest correlation both before and during cancer treatment was found in physical function, role function and fatigue (0.54 - 0.63). According to Pearson, the relation should be more than 0.40. A weak correlation between emotional, role and physical functions was identified in the validity test (Aaronson et al., 1993).

Table 4. Cronbach’s Alpha α test in EORTC (Papers I-III)

EORTC	Paper I	Paper II	Paper III
Global health status/QLQ	0.77	0.73	0.77
Functional scale			
Physical function (PF)	0.82	0.79	0.78
Role function (RF)	0.94	0.92	0.92
Emotional function (EF)	0.65	0.63	0.61
Cognitive function (CF)	0.45	0.38	0.43
Social function (SF)	0.98	0.98	0.97
Symptom scale			
Fatigue (FA)	0.78	0.75	0.76
Nausea & vomiting (NV)	0.79	0.81	0.80
Pain (PA)	0.88	0.89	0.92

Assessment of activities of daily living

Activity of daily living (ADL) was assessed using the KATZ Activities of Daily Living-Index (KATZ ADL-index) (Katz and Akpom, 1976) and the extended version developed by Sonn (1991). Katz et al, (1976) summarizes an individual’s overall performance based on Instrumental Activities of Daily Living (IADL) consists of four functions: shopping,

cleaning, transport and cooking and six functions in Personal Activities of Daily Living (PADL): washing; dressing; going to the toilet; transfer, continence; and feeding (Sonn and Asberg, 1991). By using the extended version of the KATZ index it is possible to obtain a more complete picture of the participant's ability at home and in the close surroundings (Sonn and Asberg, 1991). Questions concern for example 'Cooking (go to kitchen, prepare supper and make the table)'. The response format scores consist of a 3-point format scale ranging from one to three. 1=independent, 2=partly dependent, 3=dependent (continence: 1=no, 2=yes and 3=catheter/ostomy). In the mentioned example the alternative answers were: 1=cooking alone, 2=do not prepare supper or only prepare pre-prepared meals' and 3=do not prepare any meals. IADL was scored ranging from 4 to 12, and PADL from 6 to 16. The 10-graded ADL scale has shown both good validity and reliability in both an outpatient sample as well as in a population of 76-year people in Sweden (Sonn, 1996). The Cronbach's Alpha test for IADL and PADL was acceptable (IADL α =0.75-0.81 and PADL α =0.82-0.87) (Table 5). The ten-graded ADL scale has primarily been used in geriatric persons in the Nordic countries, but has not been tested in cancer patients, elderly or otherwise. Goodwin has used the Katz PADL in elderly cancer patients aged 65+, but no psychometric data were reported Goodwin (Goodwin et al., 1991). In a Swedish study the reliability test identified coefficients of 0.74-0.88 (Brorsson and Asberg, 1984). Despite the scale's widespread popularity among clinicians worldwide, there is little evidence of its validity. However, Katz et al, (1970) found that the ADL correlated weakly to moderately with a mobility scale (0.50) and with a confinement scale (0.39) (Bowling, 1997).

Table 5. Cronbach's Alpha test in Katz-ADL-index (Papers I-III)

Katz ADL-Index	Paper I	Paper II	Paper III
IADL	0.81	0.75	0.76
PADL	0.85	0.87	0.82

Assessment of social network and support

In this thesis, the abbreviated version of the Interview Schedule for Social Interaction (ISSI) was used to measure the social network and support. Unden and Orth-Gomer (1989) translated a longer version of the ISSI, originally developed by Henderson and Byrne in Australia in a large study on a normal population (age younger than 65). ISSI originally consisted of four subscales (50 items) and showed good reliability and validity properties (Henderson et al, 1980). In a subsequent study, (Orth-Gomer et al., 1993) evaluated an abbreviated version of the ISSI, which was tested in a study group of 50-years-old Swedish men, and ISSI is also made applicable to a Swedish population in patients with Ischaemic Heart Disease (IHD) (age 45-70, mean age 62.6y) (Unden and Orth-Gomer, 1989, Unden et al., 1991). ISSI in its original setting requires a considerable amount of time, and Unden et al, 1989 therefore provided a short version where the distribution of scale scores was similar in the complete and in the abbreviated version. The reliability, measured as internal consistency and split-half, was satisfactory (Unden and Orth-Gomer, 1989). The psychometric properties of the instruments (the abbreviated version and the complete version) were acceptable and in agreement with the

result from the Australian study (Unden and Orth-Gomer, 1989) on a general population (Orth-Gomer and Unden, 1987). In this thesis, the abbreviated form of ISSI was used in assessing the availability and perceived adequacy of a wide range of social contracts and relationships. It builds on the imaginations of the individual and the social environment and its significance for the preservation of good health (Orth-Gomer et al., 1993, Orth-Gomer and Unden, 1987, Unden and Orth-Gomer, 1989). ADSI (Adequacy of Social Integration) & ADAT (Adequacy of Attachment) was not included in this study due to protect the participants against too many questions. The instrument is a result of a systematic review of instruments suitable for population surveys that describe social support and social influences in relation to health outcome (Orth-Gomer and Unden, 1987). ISSI consists of two subscales; AVSI and AVAT (a short 13-item version) and measure the availability of social integration and the Availability of Attachment.

'Availability of Social Integration' (AVSI), contains six questions about function and quantitative aspects of the extended network and its function, measuring aspects such as practical help, appraisal of support and self confidence (i.e. openness and sincerity in relation to network members). The six questions are about function and quantitative aspect of the patients' social network. Questions are for example 'Among your family and friends, how many persons are there who are immediately available to you, whom you can talk to frankly, without having to watch what you say?' Response alternatives are 'none', '1-2', '3-5', '6-10', '11-15' and 'more than 15'.

'Availability of Attachment' (AVAT) describes the availability of emotional support. Whether there is someone close, whether there is someone with whom to share happiness and sorrows, to lean on in difficult times and someone available for comfort. The areas are 1) relations in which interests are shared, 2) relations who give reassurance of personal observation, and 3) alliances which give a possibility for both instrumental and other types of support in difficult situations. Questions are formulated as for example 'Do you feel there is one particular person who feels very close to you?' Response alternatives are 'yes' and 'no'. ISSI was transformed as indicated by Henderson (1980, 1980) and the questions allotted to each dimension were added up; AVSI 1 to 6 and AVAT 1 to 6; higher score indicate higher social network and attachment (Henderson et al., 1980, Henderson et al., 1980).

The reliability analysis for AVSI and for AVAT was acceptable (AVAT: $\alpha = 0.66-0.76$ and AVSI: $\alpha = 0.70-0.76$) (Table). The two subscales should not be put together (Henderson et al., 1980, Henderson et al., 1980). Mean scores were calculated and high scores indicating high support (Unden et al., 1991). Lalos and Eisemann (1999) tested the abbreviated form of ISSI (AVSI and AVAT) in 60 Swedish women with cervical and endometrial cancer (the upper age limit was set at 60 years) (Lalos and Eisemann, 1999). It was reported that the scores were within normal limits with reference to Unden, Orth-Gomer, and Elofsson (1991). ISSI has to the author's knowledge not been tested on Danish patients with cancer, but has been used in a Nordic multicentre study in person with schizophrenia, however, no psychometric tests were reported (Sorgaard et al., 2001). Other psychometric tests performed by Undén and Orth-Gomér (1989) identified the correlation coefficients between the ISSI scales at 0.75 ($P < 0.001$) in the abbreviated version. The construct validity was tested and a correlation between the four dimensions

(the complete version of ISSI) in relation to personality assessments ranged from -0.18 to -0.31 (Bowling, 1997).

Table 6. Cronbach's Alpha test in ISSI (Papers I-III)

ISSI	Paper I	Paper II	Paper III
AVSI	0.76	0.66	0.67
AVAT	0.73	0.76	0.70

Assessment of hope

Hope was measured using Nowotny's Hope Scale (NHS), which is an instrument developed to measure it in a general adult population after a stressful event (such as cancer). NHS was developed on the basis of an extensive review of the literature on hope in the fields of psychology, psychiatry, theology and nursing, and the scale has been tested on persons with cancer (Nowotny, 1989) but not specifically on elderly persons. In this study, NHS was translated both from English/American to Danish and from Norwegian to Danish according to internationally accepted guidelines (Streiner and Norman, 1989). The scale consists of 29 questions on six dimensions, and provides detailed information on different aspects of hope in separate subscales. In a factor analysis, Nowotny proved that the results supported the six dimensions of hope scale, also supported by an expert panel. The six dimensions are 'confidence' (eight items), 'related to others' (five items), 'future is possible' (five items), 'spiritual beliefs' (three items), 'active involvement' (five items) and 'comes from within' (three items). Questions are for example 'I feel confident about the outcome of this event/situation', or 'Sometimes I feel I am all alone'. The response format scores consist of a 4-point scale ranging from one to four 'strongly agree', 'agree', 'disagree' to 'strongly disagree' and is easy to administer and to score except the 'spiritual beliefs' (Rustoen and Moum, 1997). It takes about 10 minutes to complete the scale. Both positive and negative leaning questions are included. The scoring of NHS was in accordance with the methodology developed by Nowotny, with scores ranging from 29-116; the higher the score the higher the degree of hope (Nowotny, 1989). A score from 29-50 indicates 'hopelessness', 51-72 'low hope', 73-94 'moderately hopeful' and 95-116 'hopeful' (Nowotny, 1989).

The reliability analysis for NHS in this thesis reaches satisfactory levels of Cronbach's alpha, except for 'comes from within' ($\alpha=0.20-0.30$) (Table 7). Nowotny found Cronbach's alpha from 0.72-0.90 on the six subscales ($n=306$) (Nowotny, 1986), and Rustoen found 0.53-0.94 and 0.71-0.89 on re-test; 0.53 was on 'active involvement' but in the re-test it was found as 0.71 (Rustoen and Moum, 1997). The internal consistency has been found to be high in different cultures such as Japan, Norway Spain, the UK, and the USA, and suggests that hope is a phenomenon that is relatively homogeneous across different cultures (Rustoen and Moum, 1997). NHS was applied, too, in a Norwegian study including newly diagnosed cancer patients (age ranging from 26-78 years, primarily women) with a satisfactory outcome, while NHS to the author's knowledge has not previously been used in a Danish context. Other psychometric tests on the Norwegian

version of NHS has been performed by Rustoen (1997), who identified a Pearson's $r=0.81$ for the entire instrument 3-4 weeks after the first test in the test-retest reliability. The construct validity was tested and a correlation between the different subscales ranged from -0.16 to 0.73 (Rustoen and Moum, 1997), reflecting a major methodological problem for the NHS.

Table 7. Cronbach's Alpha test in Nowotny's Hope Scale (Papers I-III)

Nowotny's Hope Scale	Paper I	Paper II	Paper III
NHS	0.84	0.88	0.87
Confidence	0.64	0.73	0.74
Related to others	0.71	0.75	0.77
Future is possible	0.73	0.73	0.74
Spiritual beliefs	0.89	0.87	0.88
Active involvement	0.69	0.71	0.74
Comes from within	0.30	0.26	0.20

The open-ended interviews

The findings of Paper IV were based on open-ended interviews. The purpose of the phenomenological interview was to get closer to the lived experience of the patients and to listen carefully to the meaning of getting cancer in old age. According to Morse and Richard (2002) data cannot be characterised as 'collected', however, instead they are created in a particular form according to the method used (Morse and Richards, 2002). In other words, researchers make data in collaboration with their participants. Making data is not a passive process – rather it is a cognitive process that requires investment on the part of the researcher (Morse and Richards, 2002). The relation between the participant and the interviewer during the interviews is a meeting on two levels with a dual interest. The interviews occur both as an 'unnatural situation' where the participant is a part of research, and as a personal relationship built on intimacy. Morse and Richards (2002) compares the interview situation with 'an intimate and personal sharing of confidence with friend'. It means that researchers must take that in receiving the experiences shared by the participants. They always only 'borrow' other people's experiences and reflections. The minimal demand is to be humble both in relation to the participants and in relation to what was shared. Furthermore, the researcher needs to examine their own assumptions, and to make own prejudices and pre-understanding clear in relation to the problem and to their conduct of the study (Kvale, 1996). Awareness of how pre-understanding affects the process of research is important in: how the problem to be studied was chosen, how it is defined, how the research questions are formulated, the choice of method and so on. It is also important that pre-understanding is recognized and restrained during the research process (Dahlberg et al., 2001, Giorgi, 1985). However, pre-understanding might partly be unconscious and may therefore be difficult to reach (Dahlberg et al., 2001, Giorgi, 1985). The role as a nurse and a researcher is manifest in the same person and needs to be dealt with in consciousness, both in practical and methodological terms. The author of this thesis is a registered nurse (RN) and oncology nurse (ON) with experience within the field of oncology, haematology and palliative care. Experience from clinical practice, is however, primarily with children, young and middle-aged people with cancer. Deeper understanding of elderly persons has changed during this thesis as the author became

more familiar with their experience and situation, primarily through performing the structured interviews in the follow-up study.

All interviews were conducted by the author, and each interview took place in people's homes. Each interview was conducted as a conversation (Kvale, 1996), and the interviewer strove for each person to be interviewed alone and the setting to be a comfortable and confidential situation. The participant was offered the opportunity to tell his or her story by the interviewer; the opening invitation/'grand tour-question' (Morse and Richards, 2002) was: 'I am interested in what it is like to live with cancer in old age. Please tell me about your experience'. Unstructured interviewing allowed the interviewer to follow the participants' lead, to ask clarifying questions, and to facilitate the expression of the participants' lived experience with minimal interruption (Morse and Richards, 2002). This was in accordance with the interview guide, as it allowed the participants to be encouraged to tell their own stories in their own way. While performing the interviews, it was not always obvious that the author understood what the experiences meant to the participants. It was an ethical challenge to ensure that the perspective of the participants formed the base for the understanding. In concrete, it meant that the author had to ask elaborating questions. One of the assumptions of empathy is to unite closeness and distance (Fog, 1994). Distance generates a sort of space between the interviewer and the participant with concern for the person's integrity in such a way that the person can preserve it.

The interviews were audio-taped and lasted for about 60-90 minutes, except one that was 15 minutes long due to frailty of the interviewee. The tape-recorder was turned off twice during two interviews due to issues being personally sensitive. The interviews were performed during the period of June-August 2002.

ANALYSES

Statistical analyses

Statistical analyses were performed to describe QoL and related conditions at baseline, three-month follow up and six month follow up, to investigate changes between the different points, to identify factors associated with low QoL and to analyse the influence of potential risk factors for decreased QoL over the follow-up period. As the continuous variables in the study were all judged to be skewed, non-parametric test were used throughout to analyse differences between groups and between time points.

Group comparisons

Differences between two independent groups (four age categories 65-69, 70-74, 75-79, and 80+ years) (women and men) (stable and deteriorated QoL), were analyzed using Pearson's Chi-square test when data were on a nominal or categorical scale (Paper I-III). For differences between age groups, Kruskal-Wallis one-way analysis of variance was used for analyzing ordinal scale data (Paper I). When analyzing differences between independent groups (stable and deteriorated in QoL, and between participants and non-participants) Mann-Whitney U test were used for interval/continuous data (Paper II-III).

Differences between related groups McNemar test (nominal or categorical data) was used to analyze differences between baseline and three months' follow-up (Paper II). For analysis of differences between related groups (differences between baseline and three months' follow-up) the Wilcoxon's Signed Rank test (ordinal scale data) (Altman, 1991) (Paper II) was used. To identify group differences (related groups) between baseline, three and six months after the Cochran Q test was used (Altman, 1991) (nominal/categorical data) as well as comparison within the group 'stable in QoL' and the group 'deteriorated in QoL' (Paper III). To identify group differences (related groups) between baseline, three and six months after the Friedman test was used (Altman, 1991) (ordinal scale data) as well as comparison within the group 'stable in QoL' and the group 'deteriorated in QoL' (Paper III).

To identify significant differences between age groups the Mann Whitney U-test was used as post hoc test with a Bonferroni correction (Bland and Altman, 1995) for multiple comparisons with a reduced p-value ($P < 0.013$) (Paper I). To determine whether there were statistically significant differences between baseline, three months and six months Pair-wise post-hoc comparisons were performed with a Bonferroni correction for multiple comparisons (reduced $P < 0.017$) (McNemar test and Wilcoxon's Signed Rank test). To determine whether there were statistically significant differences between baseline, three months and six months within the 'stable in QoL-group' vs. 'deteriorated in QoL-group' Pair-wise post-hoc comparisons were performed with a Bonferroni correction for multiple comparisons (reduced $P < 0.017$) (Cochran Q test) (Petrie and Caroline, 2000) (Paper III).

According to King (1996) changes in EORTC QLQ-C30 scores with 10 units or more should be considered clinically significant. Following this recommendation a new variable 'Global health status/QoL deteriorated with 10 units' was created dichotomised into those experiencing a deterioration in QoL with 10 units or more between baseline and 3-month follow-up, and those experiencing a deterioration in QoL with 10 units or more between baseline and 6-month follow-up ('Deteriorated QoL') vs. others ('Stable QoL').

Logistic regression analyses

Logistic regression analyses were performed with Global health status/QoL (Paper I-III), (Functional scale and Symptom scale=Paper I) as dependent variable/s, each dichotomized with the first quartile (Symptom scale third) as cut-off. Scores for AVSI, AVAT, P-ADL, I-ADL Nowotny's hope scale were dichotomized with the first or third quartile as cut-off, depending on which values were expected to constitute risk for low/deteriorated QoL. Categorical variables were dummy coded in the following way. Marital status (not married, single, divorced, widowed, separated vs. married/cohabiting), cancer diagnosis (breast, gynaecological, lung vs. colorectal) (Paper I-III).

Multiple logistic regression analysis (forward selection, likelihood ratio) (Altman, 1991) controlling for sex and age was performed to identify risk factors for low QoL at baseline (Paper I) and low QoL at three-month follow-up (Paper II). EORTC QLQ-C30 scores at three-month follow-up were dichotomized with the first quartile as cut-off (< 50.0) to identify subjects with the lowest QoL (17.61% of the participants) (Paper II). Variables possibly predicting deteriorated QoL between baseline and at six-month follow-up

dichotomized with the first quartile as cut-off were included tested in a multiple logistic regression model (forward selection, likelihood ratio) (Paper III). Deteriorated QoL was defined as the 'low global health status/QoL' value that was dichotomized at the first quartile <50.0 (37.3% of the total sample) (Paper III). Variables that in the univariate analyses were significantly related (≥ 0.15) to the dependent variables with a P-value ≤ 0.15 in the EORTC QLQ C-30: Global Health Status/QoL (Paper I-III), Functional scale, and Symptom scale (Paper I), were included in the regression model. Despite advanced age (79+ years) not being found significant in the univariate analyses, it was included in the regression model (Paper I). Because the highest QoL was found in the colorectal cancer group, it was chosen as a reference value in relation to the other diagnosis groups (Paper I). Ninety-five percent Confidence Intervals (CI) of 95% were calculated for the Odds Ratios (OR). The Hosmer-Lemeshow test was used to evaluate the goodness-of-fit of the final regression model/the model as being worthwhile (a value greater than .05). Nagelkerke *R*-square test are given to provide an indication of the amount of variation in the dependent variable explained by the model (from a minimum value of 0 to a maximum of approximately 1) (Table I-III).

Reliability tests

In this thesis the reliability of the instruments used were measured by Cronbach's alpha (Cronbach, 1951). An acceptable alpha value should be between 0.70 and 0.90 (Streiner and Norman, 1989). Cronbach's alpha (Cronbach) was used in Paper I-III to calculate internal consistency for the instruments EORTC-QLQ-C30, NHS, KATZ ADL-index and ISSI (Table 6).

All statistical analyses were carried out using SPSS 11.5 for Windows®. P-values <0.05 were regarded as statistically significant. Descriptions of quantitative variables are given as median and Interquartile Range (IQR).

Phenomenological analysis

Giorgi's phenomenological analysis method was used (Giorgi, 1985, Giorgi, 1997). The method is descriptive and contains four steps (Giorgi, 1985). Two secretaries transcribed the interviews verbatim. Before the actual analysis, the author read the interview transcripts while listening to the tape recorded interviews and corrected or added information. The author and another researcher performed the analysis. The author and researcher discussed the findings, and agreed that the essences covered the central aspects of the interviews and illuminated the experience of elderly persons diagnosed with cancer. The first step was to achieve an overall understanding by reading the entire transcripts in order to retain a global sense of the whole. The second step was breaking of the text into meaning units by re-reading the transcripts. A thorough re-reading of the transcript constructed the meaning units each time a shift in meaning in the transcription arose, and it was marked until the next meaning unit was identified, and so on. The end of this step was a series of meaning units still expressed in the participants' own words with emphasis on the phenomenon being investigated. Texts that were not related to the phenomenon in focus were removed. This procedure was performed through each interview. The meaning

units were considered as fundamental units or expressions related to the phenomenon of 'the lived experience of cancer in old age'. The third step was to examine, probe, and re-describe (transform) each meaning unit of the participants' own language into the researchers' disciplinary language searching for essential aspects of the phenomenon. The fourth step was to reveal the essential structure and synthesise transformed meaning units into essential aspects and meaningful patterns of the essence of the phenomenon investigated, representing the lived experience of each interviewee. Finally, when all interviews had gone through these steps, a synthesis was made in relation to clusters of variation of the essence of the phenomenon investigated. In this phase, one main essence and three essences emerged from the texts, and seven constituents illuminated the meanings of these essences. During the analysis process, the authors tried to disregard their pre understanding by recalling and making it explicit, and then trying to bracket it.

ETHICAL CONSIDERATIONS

In accordance with Danish regulations and established good practice, the Danish Data Protection Agency was consulted and formal consent was sought and given for this study. The project adhered strictly to the regulations established by the Ethical Guidelines for Nursing Research in the Nordic Countries (SSN), all relevant laws and regulations in Denmark, and the Declaration of Helsinki II. With this background and the full clinical description of the project, the Ethics Committee of the County of Copenhagen found formal registration of this project unnecessary.

According to the Belmont report as described in Polit and Hungler (1999) there are three major ethical principles: the principle of beneficence, the principle of respect for human dignity, and principle of justice (Beauchamp and Childress, 1994, Polit and Hungler, 1999). *The principle of beneficence*, (involving freedom from harm and exploitation, current benefits from research, including the principle of altruism) was particularly important when conducting both structured interviews (Paper I-III) and the open-ended interviews (Paper IV). Discretion and sensitivity was one important aspect for the researcher to take into account. Since the interviews took place in the participants' own home, respect for privacy was of great significance. Since it can be emotionally difficult both to talk about and report facts and experiences related to the new and different situation for those recently diagnosed with cancer, two psychologists from the oncology unit were available to handle possible emotional reactions from the participants. Due to the sensitive issues connected with the study, the participants received the author's private mobile phone number on the written information sheet. Neither of these possibilities was used. Special attention was also paid during the interviews to signs of the interviewees becoming tired or exhausted and for possible emotions that the participants might find hard to handle. In one case, exhaustion caused by frailty led to the interviewer deciding to end the process. The interviewer made sure that she felt content again before leaving her alone (Paper IV). Some participants expressed uninited that they felt that they had an opportunity to tell about their experiences to someone who listened.

The principle of a respect for human dignity means involving the right to self-determination, full disclosure and respect (Polit and Hungler, 1999). Informed consent for participation and permission to audio tape-recording of the interviews were obtained from the

participants after an explanation of the study by the author. The purpose of the information was that the participant was comfortable to participate the study, and that he or she understood what they agreed to. Because it was planned to interview each participant at least three times, it was important to underline that they could refuse participation both during and between the interviews. In the beginning of each interview, it was ensured that the participant wanted to continue to take part in the interview study. It was made clear that they could withdraw from the study at any time, without in any way jeopardizing their contact with the oncology clinic. The confidentiality of the participants was sustained by a coding system, which made it impossible to identify individual participants. The audio-tapes and completed questionnaires (list of codes and names) were stored in a safe.

Collecting this kind of information raises specific ethical issues. One concern is how far an interview should go in probing answers. The interviewer should be prepared to follow where information might lead because it often leads to fruitful territory for those informants who wish to use the interviewing situation as an occasion for self-reflection and their own increased understanding. The ethical principle has been that the researcher must do whatever is necessary 'to protect research subjects' i.e. protect them as individuals from any misuse of the information they have shared (Løgstrup, 1956).

Principle of justice means involving the right to fair treatment and privacy (Beauchamp and Childress, 1994, Polit and Hungler, 1999). The selection of the sample was randomised and all were asked to participate regardless of e.g. sex, race, nationality political views and social status. The participants received both oral and written information about the foundation, aim, method and application about the study by the author. The outlines of the study, and the issue of voluntary participation, were made clear, in addition, potential participants were informed about the procedure to guarantee confidentiality. The author had no access to the national Central Person Registry (CPR) lists of persons or hospital case records, and participants were informed that it was their perceptions and experience that were of interest. The information consisted also of the implication of contribution, what a 'yes' implied, how many interviews it would involve, for how long time the interviews were planned to last, and the fact that the qualitative interviews would be recorded. The rights to privacy could especially be of interest on the issue of interviews, when the interviewer visits the participant's home, and hence the intrusion into people's personal life becomes a potential ethical issue. Thus, the interview must ensure that the research is not more intrusive than is needed. Therefore, the respondents were carefully informed about the purpose of the study, reminded that their participation was voluntary and that they could end their participation whenever they wanted. No other threats to the principle of justice were identified in this study. Permission to carry out the studies was given by the head nurse and the chief physician of the Oncology Clinic at the County of Copenhagen Hospital.

Whether it is justifiable from an ethical point of view to let elderly, frail people participate in research has been discussed (Chouliara et al., 2004, Morse, 2002, Morse and Doberneck, 1995, Penrod and Morse, 1997, Polit and Hungler, 1999, Wenger, 2002). To ensure quality of data in research with elderly persons with cancer represents challenges, and it is important with a patient-centred and flexible approach (Chouliara et al., 2004). From an ethical point of view it can be discussed whether a personal structured

interview about being diagnosed with cancer and being old may provoke strong emotional reactions in the elderly. It can also be discussed whether three interviews (Paper I-III) (and for 16 participants four interviews (Paper IV)) were an excessive strain to the participants. However, an interview (personal structured or open-ended) can be regarded not only as a 'data-collecting instrument' within qualitative research, but also as a therapeutic conversation with possible benefit for the participants. Even though it has been pointed that elderly and very frail persons seldom benefit personally from research (Polit and Hungler, 1999), seemingly the participants had some benefit from their participating, in terms of the possibility to share their experience with someone from the health-care system. In all human research, the researcher ought to be sensitively aware of the confidentiality of participants being protected. Moreover, the researcher needs to protect them against being an object and being strained due to participation in research. Instead, the focus needs to be on their benefit and on protecting their subjectivity.

FINDINGS

The findings from the various studies are presented in relation to time of diagnosis (baseline), three-month follow-up, and six-month follow-up. The headings are: Demographic and socio-economic data, Characteristics of those not participating at three and six months follow-up, Characteristics of those with deteriorated quality of life, Activities of daily living, Social network and support and help from healthcare system, Hope, Factors associated with low quality of life and factors predicting deteriorated quality of life. Finally, the lived experience of getting cancer in old age is presented.

Time of diagnosis (Paper I)

Demographic and socio-economic data in relation to age

The median age of the study group at baseline was 74.74 years (IQR 8.75). Between participants in the four age groups, there were no statistically significant differences in the distribution by age, sex, type of accommodation, number of years at school, last occupation, no incomes other than retirement pension and financial circumstances. A significant difference was found implying a bigger part living alone with increasing age (chi-square for trend; $P=0.002$). In total, 44.6% lived in apartments, 52.5% in their own houses and 3.0% in sheltered accommodation. The participants belonged to 'housewife or blue collar-profession' (46.5%), 'employee/civil servant' (33.7%), and 19.8% were 'self-employed'; the reported number of years at school was 8.00 (IQR 3.00) years (Table 1). In total, 27.7% reported no other incomes than retirement pension, while 12.9% reported reduced economic ability due to cancer, however, but without any significant differences between the four age groups (Table 1).

Quality of life in elderly persons with cancer

At baseline, there were no significant differences between the four age groups in the three subscales in EORTC QLQ-C30. In global health status/QoL, the total median was 66.67 (IQR 33.33), on the functional scale there was a median of 77.78 (IQR 25.56) and a median of 23.08 (IQR 20.51) on the symptoms scale. Women had a significantly lower

emotional function (median 66.67; IQR 41.67) compared to men (median 83.33; IQR 16.67) (P=0.029) (Table 7). Fatigue was the most reported complaints on the symptom scale (median 44.44; IQR 44.44), followed by insomnia (median 0.00; IQR 66.67), pain (median 16.67; IQR 33.33), and dyspnoea (median 0.00; IQR 66.67). Women (median 16.67; IQR 50.00) suffered significantly more from pain than men did (median 0.00; IQR 66.67) (P=0.020) (Table 8). Financial difficulties (median 0.00; IQR 0.00), had the lowest score on the symptom scale.

Table 8. Gender comparison of QoL at baseline

Median (Interquartile Range IQR)	Women	Men	p-value ¹
Global health status/QoL²	66.67 (33.33)	66.67 (33.33)	0.837
Functional scale²			
Physical function	66.67 (46.67)	73.33 (33.33)	0.336
Role function	66.67 (33.33)	66.67 (100.00)	0.522
Emotional function	66.67 (41.67)	83.33 (33.33)	0.029
Cognitive function	83.33 (20.83)	83.33 (16.67)	0.747
Social function	100.00 (0.00)	100.00 (33.33)	0.164
Symptom scale³			
Fatigue	44.44 (55.55)	44.44 (44.44)	0.602
Nausea and vomiting	0.00 (16.67)	0.00 (33.33)	0.512
Pain	16.67 (50.00)	0.00 (16.67)	0.020
Dyspnoea	0.00 (33.33)	0.00 (66.67)	0.167
Insomnia	16.67 (66.67)	0.00 (33.33)	0.733
Appetite loss	0.00 (33.33)	0.00 (33.33)	0.730
Constipation	0.00 (33.33)	0.00 (33.33)	0.694
Diarrhea (DI)	0.00 (33.33)	0.00 (0.00)	0.466
Financial difficulties	0.00 (0.00)	0.00 (0.00)	0.475

¹ Mann-Whitney U-test

² Higher scores indicate higher health-related quality of life

³ Lower scores indicate fewer problems

Activities of daily living

At baseline, 72.3 % were independent in all IADL functions, and 17.8% were independent in regard to PADL. Regarding IADL, 55.4% of all persons could shop independently. There were no significant differences between age groups regarding dependency in IADL and PADL, neither regarding gender (Table 9). Out of the 101 persons, 33.7% reported incontinence. No one was dependent on assistance regarding food intake.

Table 9. Gender comparison of activities of daily living baseline

Median (Interquartile Range IQR)	Women	Men	p-value ¹
ADL²			
IADL (4-12)	6.00 (5.00)	7.00 (4.00)	0.265
PADL (6-18)	6.00 (1.00)	6.00 (1.00)	0.307

¹Mann-Whitney U-test² Higher scores indicate higher dependency

Social network and support, and help from the health-care system

Altogether, 90.1% of the participants had adult children, 85.1 % had grandchildren, and no significant differences with respect to age groups were found regarding relation to spouse, adult children, grandchildren, or friends. At baseline, 61.5% received help from adult children, while 24.4% received help from grandchildren. There were significant differences ($P < 0.001$) between the age groups in AVSI with the oldest age group having significantly lower score compared to each of the other groups. However, no gender difference was identified in AVSI. The total score of AVSI was in median 3.0 (IQR 3.0) and AVAT (median 6.0; IQR 1.0), with no significant gender difference (Table 10). The oldest age group (80+ years) had, to a significant extent ($P = 0.001$), fewer number of visits to the hospital within the last six months (73.9%) compared to the age groups 65-69 years and 70-74 (100% for both), and received more home help service (56.5%) compared with age groups 65-69 years and 70-74 (16.7% and 21.4%, respectively). In total, 75.8% of the total group needed more help in daily living, however, with no significant differences among the four age groups.

Table 10. Gender comparison of social network and support at baseline

Median (Interquartile Range IQR)	Women	Men	p-value ¹
ISSI²			
AVSI (1-6)	3.00 (3.00)	4.00 (3.00)	0.296
AVAT (1-6)	6.00 (1.00)	6.00 (1.00)	0.098

¹Mann-Whitney U-test² Higher scores indicate higher social integration and network

Hope

At baseline, the total median score for hope was 85.00 (IQR 14.50) which, according to the classification developed by Nowotny, was 'moderately hopeful' (Nowotny, 1986). No significant differences between the four age groups were identified though, women had significantly ($P = 0.006$) higher spiritual beliefs (median 6.00 (IQR 6.00)) compared to men (median 3.00 (IQR 4.00)) (Table 11). However, differences between the four age groups were found in the subscale depicting 'future is possible' ($P = 0.003$) with a

significantly lower score in the oldest age group (median 13.00; IQR 4.00) compared with 65-69 years (median 15.00 ; IQR 3.75).

Table 11. Gender comparison of hope at baseline

Median (Interquartile Range IQR)	Women	Men	p-value ¹
NHS (29-116)²	85.50 (14.25)	85.00 (17.00)	0.812
Confidence (8-32)	25.00 (4.25)	25.00 (6.00)	0.187
Related to others (5-20)	18.00 (5.00)	18.00 (3.00)	0.554
Future is possible (5-20)	14.00 (5.00)	13.00 (5.00)	0.605
Spiritual beliefs (3-12)	6.00 (6.00)	3.00 (4.00)	0.006
Active involvement (5-20)	14.00 (4.00)	14.00 (3.00)	0.359
Comes from within (3-12)	11.00 (1.00)	11.00 (1.009)	0.601

¹Mann-Whitney U-test

² Higher scores indicate higher hope

Factors associated with low quality of life

Factors significantly associated with low quality of life in global health status/QoL were ‘no income other than retirement pension’ (OR 3.709, 95% CI 1.241-11.080), ‘low level of hope’ (OR 7.382, 95% CI 2.365-23.042) and ‘lung cancer (reference category: colorectal cancer)’ (OR 5.650, 95% CI 1.434-22.260) (Table 12).

Factors significantly associated with low quality of life on functional scale were ‘The disease has not come to an end’ (OR 6.863, 95% CI 1.649-28.564), ‘need more help in daily living’ (OR 6.275, 95% CI 1.659-23.727) and ‘dependency in PADL’ (OR 6.817, 95% CI 1.892-24.556) (Table 12).

On symptom scale, factors significantly associated with low quality of life were ‘no income other than retirement pension’ (OR 3.389, 95% CI 1.047-11.953), ‘low level of hope’ (OR 6.203, 95% CI 1.849-20.812), ‘lung cancer’ (OR 11.943, 95% CI 2.151-66.318) and ‘getting help from adult children’ (OR 4.520, 95% CI 1.400-14.591) (Table 12).

Table 12. Factors associated with low quality of life in EORTC QLQ C-30 (the three subscales)

	Odds Ratio	95% CI for OR	p-value
Dependent Variable: Global health status/QoL¹			
No other incomes than retirement pension	3.709	1.241-11.080	0.019
Low level of Hope	7.382	2.365-23.042	0.001
Colorectal cancer			0.023
Lung cancer	5.650	1.434-22.260	0.013
Breast cancer	0.899	0.202-4.009	0.889
Gynaecological cancer	0.694	0.148-3.260	0.643
Dependent Variable: Functional scale²			
Cancer disease has not stopped	6.863	1.649-28.564	0.008
Contact with General Practitioner (GP)	5.846	0.998-34.236	0.050
Need more help in daily living	6.275	1.659-23.727	0.007
Dependent in PADL	6.817	1.892-24.556	0.003
Dependent Variable: Symptom scale³			
No other incomes than retirement pension	3.386	1.047-10.953	0.042
Low Level of Hope	6.203	1.849-20.812	0.003
Colorectal cancer			0.006
Lung cancer	11.943	2.151-66.318	0.005
Breast cancer	1.604	0.298-8.628	0.582
Gynaecological cancer	0.654	0.116-3.674	0.630
Getting help from grown up children	4.520	1.400-14.591	0.012
Multiple logistic regression stepwise (LR) Forward Stepwise (Likelihood Ratio) controlling for sex and age			
Hosmer and Lemeshow goodness-of-fit test:		Global health status/QoL = 0.739 Functional scale = 0.712 Symptom scale = 0.801	
Nagelkerke R Square		Global health status/QoL = 0.343 Functional scale = 0.359 Symptom scale = 0.427	

Three-month follow-up (Paper II)

Demographic and socio-economic data

The median age of the study group three months after diagnosis was 75.48; IQR 8,35 (76.5% women and 23.5% men). At three-month follow-up, significant sex differences were identified in those married or cohabiting (41.5% women and 70.00% men, P=0.026) and in 'no income other than retirement pension', which was primarily women (30.8%, P=0.019).

Characteristics of those not participating at three months follow-up

Those not participating at three-month follow-up study (n=16) had a median age of 71.6 years (IQR 12.03) and those who continued participation (n=85) had a median age of 75.48 years (IQR 8.35) (NS). Sex distribution was 62.5% women and 37.5% men; 56.3% were married or cohabiting. Those not participating at the three-month follow-up

were: 3 with colorectal cancer, 4 with gynaecological cancer and 9 with lung cancer. In EORTC QLQ-C30 those not participating had significantly lower scores at baseline in global health status/QoL (median 50.00; IQR 45.83) than those continuing (median 75.00; IQR 33.33) ($P=0.007$). On functional scales a significant difference was found in physical function (median 33.33; IQR 53.33) compared to those continuing (median 73.33; IQR 38.33). In addition, significant difference was found ($P=0.006$) in role function (median 16.67; IQR 9.17) compared to those continuing (median 83.33; IQR 33.33) ($P=0.003$). On the symptom scales significant difference was found in fatigue (median 66.67; IQR 52.78) vs. those continuing (median 44.44; IQR 44.44) ($P=0.022$) and in pain (median 33.33; IQR 45.83) vs. those continuing (median 16.67; IQR 33.33) ($P=0.044$). In addition, significant difference was identified in dyspnoea (median 66.67; IQR 66.67) vs. those continuing (median 0.00; IQR 33.33) ($P=0.022$) and in appetite loss (median 50.00; IQR 91.67) vs. those continuing (median 0.00; IQR 33.33) ($P=0.018$). Significantly more dependency were identified in IADL (median 10.00; IQR 4.75) vs. those continuing (median 6.00; IQR 4.00) ($P\leq 0.001$) and PADL (median 7.00; IQR 3.00) vs. those continuing (median 6.00; IQR 1.00) ($P=0.044$). Those not participating in the follow-up study had at baseline significantly more help from grandchildren (43.8%) than those who continued participation (16.5%) ($P=0.028$).

Quality of life in elderly persons with cancer

The global health status/QoL showed no significant change in quality of life score between baseline (median 75.00; IQR 33.33) and the three-month follow up (median 66.67; IQR 33.33). Fatigue was the most common symptom at three-month follow-up (median 44.44 (IQR 44.44), followed by pain (median 16.67; IQR 50.00), insomnia (median 0.00; IQR 33.33), dyspnoea (median 0.00; IQR 33.33) and appetite loss (median 0.00; IQR 33.33), but with no significant differences between baseline and three months. Women had significantly more pain at three-month follow-up than men did (median 0.00, IQR 16.67) ($P=0.019$) (Table 13).

Table 13. Gender comparison of QoL at three-month follow-up

Medians (Interquartile Range IQR)	Women	Men	p-value ¹
Global health status/QoL	75.00 (33.33)	66.67 (29.17)	0.930
Functional scale			
Physical function	70.00 (40.00)	80.00 (33.33)	0.126
Role function	75.00 (33.33)	75.57 (50.00)	0.720
Emotional function	70.83 (41.67)	91.67 (29.17)	0.043
Cognitive function	91.67 (16.67)	83.33 (16.67)	0.908
Social function	100.00 (0.00)	100.00 (25.00)	0.314
Symptom scale			
Fatigue	44.44 (44.44)	33.33 (33.33)	0.426
Nausea and vomiting	0.00 (16.67)	0.00 (33.33)	0.425
Pain	16.67 (50.00)	0.00 (16.67)	0.019
Dyspnoea	0.00 (33.33)	0.00 (50.00)	0.864
Insomnia	0.00 (66.67)	33.33 (66.67)	0.571
Appetite loss	0.00 (33.33)	0.00 (33.33)	0.658
Constipation	0.00 (33.33)	0.00 (16.67)	0.467
Diarrhea (DI)	0.00 (33.33)	0.00 (33.33)	0.905
Financial difficulties	0.00 (0.00)	0.00 (0.00)	0.549

¹Mann-Whitney U-test

Characteristics of those deteriorated quality of life

In total, 27.1% (n=23) had decreased global QoL with ≥ 10 units in global health status/QoL, whereas 72.9% (n=62) experienced no clinically significant deterioration in global QoL. Of those with deteriorated QoL, 73.9% were women and 26.1% men. In total, 82.6% were told that the cancer disease was not over, compared with those with stable QoL (53.2%) (P=0.014). Moreover, those who deteriorated in QoL had less nausea and vomiting at baseline (median 0.00; IQR 0.00) than those stable (median 0.00; IQR 33.33) (P=0.046), they had higher score in Nowotny's Hope Scale 'related to others' at baseline (median 19.00; IQR 3.00) vs. those stable (median 17.00; IQR 4.25) (P=0.042) and were more dependent in PADL at baseline (median 7.00; IQR 1.00) vs. those stable (median 6.00; IQR 1.00) (P=0.023).

Activities of daily living

At three-month follow-up 80% was independent in IADL, and 61.2% were independent in PADL. Regarding IADL, 55.4% of all persons were independent in shopping. No significance differences were identified over the first three months in need of IADL (median 6.00; IQR 4.00) or PADL (median 6.00; IQR 1.00) (three-month follow-up value). No significant gender differences were identified in IADL or PADL (Table 14).

Table 14. Gender comparison of activities of daily living at three-month follow-up

Median (Interquartile Range IQR)	Women	Men	p-value ¹
ADL			
IADL (4-12)	6.00 (4.00)	6.00 (3.00)	0.740
PADL (6-18)	6.00 (1.00)	6.00 (0.50)	0.203

¹Mann-Whitney U-test

Social network and support, and help from the health-care system

No significant differences were identified in variables relating to need for more help in daily living, getting help from adult children and getting help from grandchildren over the three first months. At baseline, 51.8 % received help from adult children, whereas 56.5% received help three months after, and 16.5 % received help from grandchildren at baseline and 23.53% months after. From baseline to three-month follow-up fewer had contact with their GP (P=0.004) in the total group (84.7% at baseline and 63.5% at three-month follow-up). It was primarily women (40.0%) who three months after were in contact with home help service compared to men (15%), (P=0.039). Regarding hospital periods over the last three months (27.1% vs. 34.1%, respectively), and in contact with the district nurse services (24.7% vs. 23.5%, respectively), no significant differences were identified regarding gender. A median value in AVAT was found to be 6.00 (IQR 1.00) at baseline and three-month follow-up. Significant differences were identified in AVSI (P=0.046) indicating a perceived lower social network at the three months follow up (median 4.00; IQR 3.00) compared with baseline (median 3.00; IQR 3.00). However, no gender differences were found in neither AVSI nor AVAT (Table 15).

Table 15. Gender comparison of social network and support at three-month follow-up

Median (Interquartile Range IQR)	Women	Men	p-value ¹
ISSI			
AVSI (1-6)	3.00 (3.00)	4.00 (2.00)	0.162
AVAT (1-6)	6.00(1.00)	5.00 (1.00)	0.073

¹Mann-Whitney U-test

Hope

No significant differences in the total hope score between baseline and three months was found. However, there was a significantly lower level of hope in the two subscales depicting 'confidence' (median 25.00; IQR 5.00 vs. median 24.00; 4.50) (P=0.003), and 'comes from within' (median 11.00; IQR 1.00 vs. median 11.00; 2.00) (P<0.001) at three-month follow up. No gender differences were identified over the three-month period (Table 16).

Table 16. Gender comparison of hope at three-month follow-up

Median (Interquartile Range IQR)	Women	Men	p-value ¹
Nowotny's Hope scale (29-116)	85.50 (14.00)	88.00 (15.50)	0.607
Confidence (8-32)	25.00 (4.00)	25.00 (6.00)	0.150
Related to others (5-20)	18.00 (4.00)	18.00 (3.50)	0.401
Future is possible (5-20)	13.00 (5.00)	14.00 (5.00)	0.955
Spiritual beliefs (3-12)	5.50 (5.00)	3.00 (3.00)	0.056
Active involvement (5-20)	13.50 (4.00)	15.00 (4.50)	0.141
Comes from within (3-12)	11.00 (1.00)	11.00 (1.00)	0.118

¹Mann-Whitney U-test

Factors associated with low global quality of life at three-month follow-up

No baseline variables were predicted significantly deteriorated QoL at three-month follow-up, whereas factors associated with low QoL at three-month follow-up were identified. The multiple logistic regression analysis showed that 'Reduced economic ability due to the cancer disease' (OR 4.548, 95% CI 1.029-20.100), 'Low level of hope' (OR 7.036, 95% CI 1.669-29.651) and 'Dependent in IADL' (OR 7.106, 95% CI 1.821-27.726) were significantly associated with low global QoL at three-month follow-up (Table 17).

Table 17. Factors associated with low quality of life in EORTC QLQ-C30 at 3-month follow-up

	Odds Ratio	95% CI for OR	P-value
Dependent variable: Low Global Health Status/QoL¹			
Reduced economic ability due to the cancer disease	4.549	1.030-20.085	0.046
Low level of hope	6.426	1.543-26.761	0.011
Dependent in IADL	7.177	1.831-28.132	0.005

Multiple logistic regression stepwise (LR) Forward Stepwise (Likelihood Ratio) controlling for sex and age

Hosmer and Lemeshow goodness-of-fit test: Global Health Status/QoL P-value = 0.548
Nagelkerke R Square Global Health Status/QoL = 0.350

Six-month follow-up (Paper III)

Demographic and socio-economic data

The median age of the study group at six months follow-up was 75.49 (IQR 8.7). In total, 46.7% were married or cohabited (Table 1) (35.1% woman and 72.2% men, P=0.006) (two women were widowed within the first six months). At six-month follow-up, 60.0% were told that the cancer had not come to an end, however, no significant gender differences were identified.

Characteristics of those not participating at six months follow-up

Those not participating at the six-month follow-up (n=26) had a median age of 73.90 (IQR 9.88). Sex distribution was 65.4% women and 34.6% men; 61.5% were married or cohabiting. Significant differences were found in global health status/QoL (median 50.00; IQR 50.00) vs. those continuing (median 75.00; IQR 33.33) (P=0.018), physical function (median 46.67; IQR 50.00) vs. those continuing (median 73.33; IQR 35.00) (P=0.003) and role function (median 66.67; IQR 87.50) vs. those continuing (median 100.00; IQR 33.33) (P=0.003). Those not participating at the six-month follow-up reported at baseline significantly more often fatigue (median 66.67; IQR 44.44) vs. those continuing (median 38.89; IQR 22.22) (P=0.007) and dyspnoea (median 33.33; IQR 67.67) vs. those continuing (median 0.00; IQR 33.33) (P=0.025) compared with those continuing participation. Significant differences were also found in IADL (median 8.50; IQR 5.25) vs. those continuing (median 6.00; IQR 4.00) (P≤0.001) and (median 7.00; IQR 3.00) vs. those continuing (median 6.00; IQR 1.00) PADL (P=0.004). A significant difference was identified in Nowotny's Hope Scale in 'comes from within' (median 10.00; IQR 1.25) vs. those continuing (median 11.00; IQR 1.00) with non-participants having less 'inner strength' than those continuing participation (P=0.005).

Quality of life in elderly persons with cancer

The global health status/QoL showed no significant difference over the six months, neither regarding gender (Table 18). However, differences between the three measurements were found in the emotional function, with a significantly lower score at baseline (median 75.00; IQR 41.67) compared with three months later (median 83.33; IQR 33.33) (P=0.009). In nausea and vomiting, a significant reduction was identified over time (P=0.003), compared to the baseline (median 0.00; IQR 16.67) and three months after (median 0.00; IQR 16.67), and from baseline (median 0.00; IQR 16.67) to six months after (median 0.00; IQR 0.00). Fatigue (median 33.33; IQR 33.33; six-month value), insomnia (median 33.33; IQR 66.67; six-month value) and pain (median 0.00; IQR 33.33; six-month value) were the most frequent complaints on the symptom scale with no significant differences over time.

Table 18. Gender comparison of QoL at six months follow-up

Median (Interquartile Range IQR)	Women	Men	p-value ¹
Global health status/QoL	75.00 (33.33)	66.67 (25.00)	0.955
Functional scale			
Physical function	73.33 (40.00)	83.33 (26.67)	0.026
Role function	83.33 (33.33)	100.00 (33.33)	0.481
Emotional function	75.00 (41.67)	87.50 (27.08)	0.091
Cognitive function	83.33 (25.00)	83.33 (16.67)	0.810
Social function	100.00 (0.00)	100.00 (4.17)	0.784
Symptom scale			
Fatigue	44.44 (44.44)	33.33 (25.00)	0.268
Nausea and vomiting	0.00 (16.67)	0.00 (33.33)	0.514
Pain	16.67 (50.00)	0.00 (16.67)	0.051
Dyspnoea	0.00 (33.33)	0.00 (41.67)	0.822
Insomnia	0.00 (66.67)	16.67 (41.67)	0.962
Appetite loss	0.00 (33.33)	0.00 (33.33)	0.639
Constipation	0.00 (33.33)	0.00 (33.33)	0.567
Diarrhea (DI)	0.00 (33.33)	0.00 (33.33)	0.839
Financial difficulties	0.00 (0.00)	0.00 (0.00)	0.580

¹Mann-Whitney U-test

Characteristics of those with deteriorated quality of life

In 30.7% (n=23) of the sample, QoL deteriorated by ≥ 10 units in global health status/QoL over the first six months, whereas in 69.3% (n=52) there was no clinically significant deterioration in QoL.

Of those with decreased QoL, 78.3% were women and 21.7% were men, no significant difference. Those with deteriorated QoL from baseline to six months after had significantly more need of district nurses at baseline (43.5%) than those who were stable (13.5%) (P=0.004). Those who deteriorated in QoL had a significantly increased use of their GPs (87%, 56.5% and 69.6% from baseline to six-months follow-up) (P=0.035) and home-help service (30.4%, 47.8% and 52.2% from baseline to six-months follow-up) (P=0.015); moreover, significantly more help was provided by their adult children (47.8%, 69.6% and 69.9% from baseline to six-months follow-up) (P=0.008). Moreover, they were significantly more dependent in IADL (median 6.00; IQR 5.00; median 7.00; IQR 5.00 and median 8.00; IQR 6.00 from baseline to six-month follow-up) (P=0.002). Social function decreased significantly (P=0.018) from baseline (median 100.00; IQR 0.00) to six months after (median 100.00; IQR 66.67). Hope (median 86.00; IQR 9.00 vs. 81.00; IQR 18.00 vs. 81.00; IQR 13.00 respectively baseline, three-month and six-month) also decreased significantly over the six-month follow-up (P<0.001). Significant differences were found in the subscales depicting 'confidence' (median 25.00; IQR 6.00

vs. 23.00; IQR 4.00 vs. 22.00; IQR 5.00 respectively baseline, three-month and six-month) ($P \leq 0.001$), ‘active involvement’ (median 15.00; IQR 5.00 vs. 13.00; IQR 4.00 vs. 13.00; IQR 2.00 respectively baseline, three-month and six-month) ($P = 0.014$). Furthermore, in ‘comes from within’ (median 11.00; IQR 1.00 vs. 11.00; IQR 1.00 vs. 10.00; IQR 2.00 respectively baseline, three-month and six-month) significant difference was found between those whose condition deteriorated and those in which it was stable ($P = 0.002$).

Activities of daily living

In total, 45.3% were independent in IADL and 70.7% were independent in PADL after six months. No significant differences were identified in need of IADL from baseline following six months (median value at six-month follow-up 5.00 (IQR 5.00) or PADL (median value at six-month follow-up 6.00 (IQR 1.00)). Significant gender difference was found in PADL (women median 6.00; IQR 1.00, men median 6.00; IQR 0.00) ($P = 0.021$) (Table 19).

Table 19. Gender comparison of activities of daily living at six-month follow-up

Median (Interquartile Range IQR)	Women	Men	p-value ¹
ADL			
IADL (4-12)	6.00 (4.00)	6.00 (3.25)	0.904
PADL (6-18)	6.00 (1.00)	6.00 (0.00)	0.021

¹Mann-Whitney U-test

Social network and support, and help from the health-care system

Altogether, 86.7% had adult children and 84% had grandchildren. Assistance from adult children (59.1% (baseline), 66.7% (three-month) and 65.2% (six-month)) and grandchildren (19.0% (baseline), 25.8% (three-month) and 33.3% (six-month)) increased significantly over the six months respectively $P = 0.001$ and $P \leq 0.001$. There was no significant difference during the first six months in either social network or social support measured in AVSI (median 3.00; IQR 2.00) and AVAT (median 6.00; IQR 1.00) – six month value (Table 20). A significant difference was found in contact with GPs over six months ($P = 0.003$); the contact was primarily around the time of diagnosis: in total 84.0% at baseline, 61.2% at three-month and 73.3% at six-month follow-up. No significant differences were found in contact with home-help services and district nurses. The tasks of the district nurse were primarily reported as administration of medicine, ulcer treatment and care, dealing with complications after surgery, instruction in how to handle colostomy, help with frail spouses, and finally statutory preventive visits from district nurses (according to Danish Law offered from age 75).

Table 20. Gender social network and support at six months follow-up

Median (Interquartile Range IQR)	Women	Men	p-value ¹
ISSI			
AVSI (1-6)	3.00 (3.00)	4.50 (1.25)	0.090
AVAT (1-6)	6.00 (1.00)	5.00 (1.00)	0.086

¹Mann-Whitney U-test

Hope

Significantly decreased scores occurred in hope from baseline to six months (86.00; IQR 14.00 (baseline), 84.00; IQR 15.00 (three-month) and 83.00; IQR 13.00 (six-month)) (P=0.027), classified as ‘moderately hopeful’. Significant decreases in the subscales depicting ‘confidence’ (25.00; IQR 5.00 (baseline), 23.00; IQR 4.00 (three-month) and 23.00; IQR 4.00 (six-month)) (P≤0.001) and ‘comes from within’ (11.00; IQR 1.00 (baseline), 11.00; IQR 2.00 (three-month) and 11.00; IQR 2.00 (six-month)) (P=0.013) was found between baseline and the three-month follow up, and between baseline and the six-month follow up (Table 21).

Table 21. Gender comparison of hope six-month follow-up

Median (Interquartile Range IQR)	Women	Men	p-value ¹
NHS (29-116)	85.00 (14.00)	88.50 (11.75)	0.261
Confidence (8-32)	25.00 (4.00)	26.00 (4.75)	0.078
Related to others (5-20)	17.00 (5.00)	17.50 (3.25)	0.558
Future is possible (5-20)	13.00 (4.50)	14.00 (5.00)	0.596
Spiritual beliefs (3-12)	5.00 (5.00)	3.00 (4.25)	0.154
Active involvement (5-20)	13.00 (4.00)	15.00 (4.50)	0.068
Comes from within (3-12)	11.00 (1.00)	11.00 (1.00)	0.046

¹Mann-Whitney U-test

Factors predicting deteriorated quality of life

The factors that predicted deteriorated global QoL from baseline to the six-month follow-up were ‘contact with district nurse’ (OR 7.206, 95% CI 1.643-31.603), ‘Need more help in daily living’ (OR 5.967, 95% CI 1.548-23.007), and ‘Low level of hope’ (OR 6.166, 95% CI 1.453-26.172), all baseline values (Table 22).

Table 22. Factors predicting deteriorated quality of life in EORTC QLQ-C30 between baseline and the six-month follow-up

	Odds Ratio	95% CI for OR	P-value
Dependent variable: Deteriorated QoL in global health status/QLQ¹			
Contact with district nurse at baseline	7.206	1.643-31.603	0.009
Need more help in daily living	5.967	1.548-23.007	0.009
Low level of hope	6.166	1.453-26.172	0.014
Multiple logistic regression stepwise (LR) Forward Stepwise (Likelihood Ratio) controlling for sex and age			
Hosmer and Lemeshow goodness-of-fit test	Global Health Status/QLQ p=0.970		
Nagelkerke R Square	Global Health Status/QLQ = 0.397		

The lived experience of getting cancer in old age (Paper IV)

The lived experience of cancer in old age was identified as *'Illness as a turning point marking old age'*. Cancer in old age implies a new life situation and worries about ending up as a cancer patient with no point of return. However, the illness could also mean a turning point with new opportunities in life reflecting optimism about the future. Being diagnosed with cancer led to a sudden awareness of oneself as growing old. On the other hand, to think about oneself as growing old seemed to have no relation to the illness and was hardly recognised yet. The main essence was represented by three essences; *'Illness means losing control'*, *'Disturbing the family balance'* and *'Life and death suddenly apparent'*, and the three essences were signified in seven constituents (Figure 3).

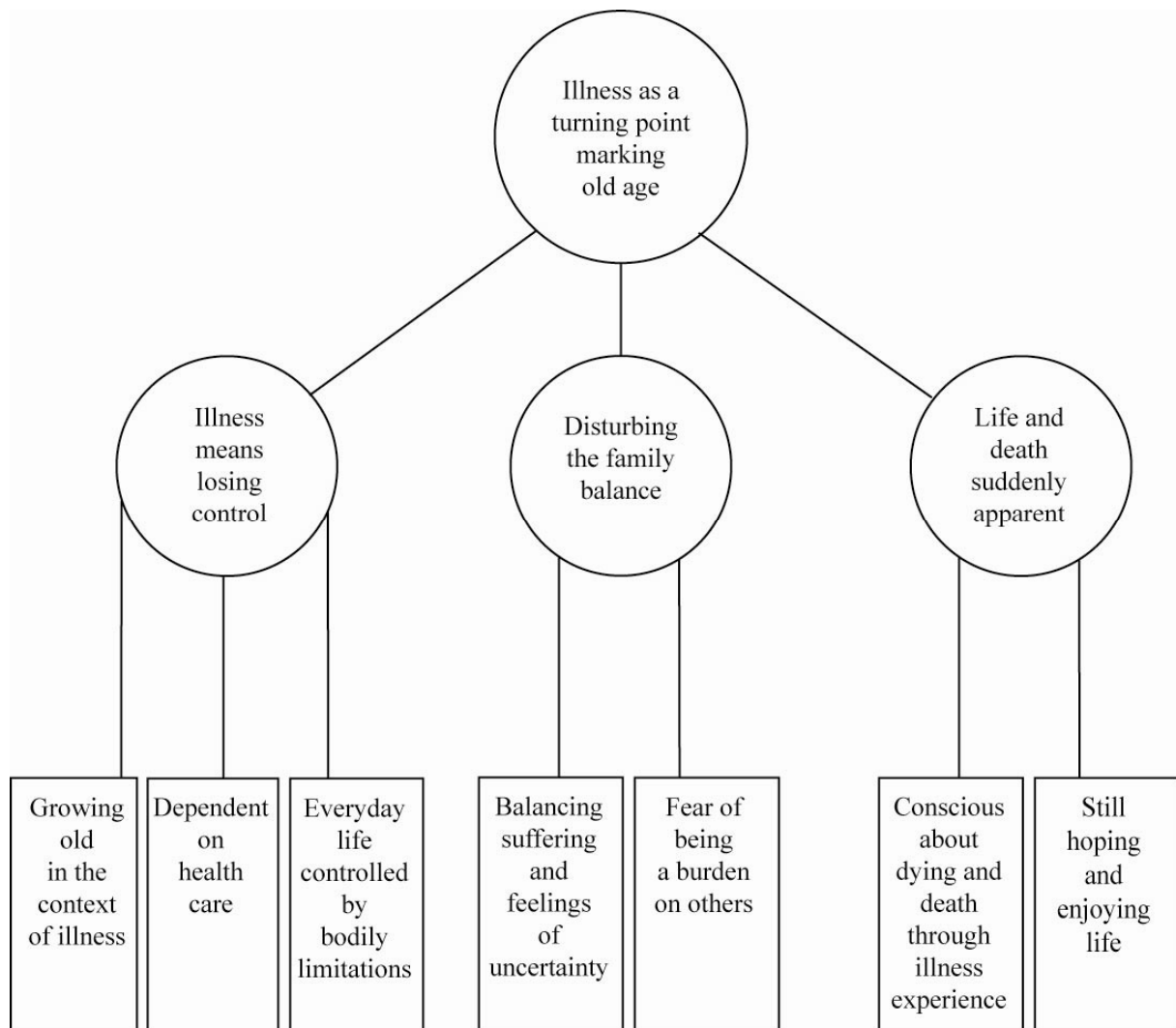


Figure 3. Main essence, three essences and seven constituents

Being diagnosed with cancer meant a turning point, and signified that the person with cancer had now entered into old age. 'Growing old in the context of illness', 'Dependence on health care' and 'Everyday life controlled by bodily limitations' were the three constituents covering the essence 'Illness means losing control'. Illness meant losing control signified that the elderly person with cancer was now old and represented both positive and negative feelings; however, it was something that was out of the person's control. Everyday life was controlled by bodily limitations and referred primarily to fatigue as the dominating complaint.

'Growing old in the context of illness' led to feelings that old age might not turn out as one expected. Remembering grandparent's ways of growing old or exceptional stories about elderly persons living in exciting ways represented looking forward to old age, whilst illness meant that these expectations could not be fulfilled. Old age was additionally related to time going fast, and as something that catches up with you, which was due to having many things yet to do. Old age was not only damaging, e.g. growing old together with a spouse over many years was talked about as positive. Accepting and realizing one's limited resources turned out to be helpful in accepting the changed

situation. 'Dependence on health care' became an essential part of getting cancer in old age. It implied a change in social identity from being an ordinary person to becoming patient. The changes were related to feelings of existential alteration, and it was demanding to look upon oneself in a new way. Decision-making about whether or not to have treatment, reflected an anguished situation between worries about possible side-effects and a feeling of being forced into making a choice. The treatment drained energy but implied a feeling of safety through the daily contact with professionals. Termination of treatment therefore created feelings of being abandoned and loss of safety, which led to anxiety dominating everyday life. 'Everyday life controlled by bodily limitations' meant that dominating inconvenient bodily complaints limited everyday life, and were associated with cancer and also with signs of being old. Pain appeared to be the first sign of cancer. Dyspnoea represented a shortcoming by having to use oxygen at home, physical limitations in activities of daily living, and fear of being suffocated. Fatigue reflected limitations in daily living, led to dependency in other people and was a sign of both growing old and of illness.

Being diagnosed with cancer in old age affected the relationship to the family, and was experienced as a turning point, implying 'disturbance in the family balance'. Having experiences of being next of kin to other persons with cancer earlier meant a sympathetic view as increased consideration was taken on to balance their suffering and uncertainty. Worries for family members and a wish not to be a burden to them arose. 'Balancing suffering and feelings of uncertainty' and 'fear of being a burden to others' were the constituents of this essence.

Balancing suffering and feelings of uncertainty became essential for the participants. It was hard to see the suffering of a spouse being unhappy and upset due to the patient's illness. When reactions were experienced as immense, they were scaring and meant a new perception of a spouse and the mutual relation. Adult children were particularly important, and there was a need to protect them against consequences of the illness. Feelings of guilt towards them led to sensitiveness to them. Grandchildren got special attention and were given high priority. Concerns about them were displayed as not involving them in illness, sparing them and taking care of them. Harmony within the family meant strength to manage the situation. An essential part of the family balance being disturbed was fear of being of burden on others. When bodily capacities and fatigue decreased the ability to manage daily life, dependency was experienced as the worst consequence of growing old and living with cancer. Dependency, which implied a feeling of being a burden to others, represented an existential feeling of having lost one's identity, and it was hard to face not being able to do simple tasks anymore. The necessity of handing over practical tasks to family members meant a wish both to get the help needed, and to manage to do practical tasks by oneself again. Getting help from others was also met with thankfulness and appreciated as an expression of care and love.

Illness meant being conscious about cancer as a life-threatening disease, covered the essence 'Life and death suddenly apparent'. Illness also meant a turning point with new opportunities in life, which was related to hope. Hope appeared as faith in life and led towards different priorities, and was reflected in an optimistic belief in life right now and as well as in the future. Consciousness about dying and death through the experience of illness, and still hoping and enjoying life were the constituents of this essence.

Consciousness about dying and death through the experience of illness was important. Death in itself did not scare the participants, whereas the path of illness at the end of life and the fear of pain were talked about as suffering. Dying was linked to feelings of despair, which lead to a wish for death to come suddenly and without pain. Life situation was depicted in a multifaceted way and when illness became inevitable, more time was spend on reflecting about lived life, living with cancer and death. A wish to live meant curiousness of still being a major part of life. Still hoping and enjoying life became essential. When illness was experienced as a threat towards life, preserving hope became of prime importance. Another approach to hope was not letting thoughts about illness become overwhelming, in recognition of being alive and hoping that recurrence of illness would not come about. Despite not being cured, constantly enjoying life seemed to be a beneficial approach in everyday life. The future was talked about as unreliable, risky and unsafe, and emphasised as a fundamental condition for all human beings.

DISCUSSION

Methodological considerations

The aim of this study was to investigate the quality of life of elderly persons from the time of their cancer diagnosis over the following six months. The quality of life and its change over time was investigated in relation to factors such as type of disease, age, socio-economic conditions, ability to perform activities of daily living, contact with health-care system, social network and support, and hope. Moreover, the aim was to illuminate the lived experience of getting cancer in old age.

In this thesis a multiple methodical design combining quantitative (Paper I-III) and qualitative (Paper IV) methods was used, and they were seen as complementary. Traditionally, quantitative and qualitative methods belong to different paradigms or worldviews, and produce different kind of knowledge (Foss and Ellefsen, 2002). Nonetheless, no single method or even combination of several methods, can capture the whole and complex reality (Foss and Ellefsen, 2002). The combination of both methods provided different kind of knowledge. The quantitative approach provides knowledge that is strong in terms of generalisation, precision and control. The strength of the qualitative method is in obtaining deeper knowledge, understanding and in revealing subjective meaning (Foss and Ellefsen, 2002, Morse and Richards, 2002, Polit and Hungler, 1999, Speziale and Carpenter, 2003). By integrating different methods, in this work a more complete picture was achieved about elderly persons newly diagnosed with cancer.

True value

True value refers to how one can establish confidence in the 'truth' of the findings, and in quantitative research it is internal and external validity, and in qualitative research it is credibility.

Internal validity refers to the degree to which the independent variables account for the results and to what extent other factors or influences can be eliminated (Kazdin, 2003).

Threats to internal validity are primarily history, maturation, testing, selection bias and attrition (Kazdin, 2003). According to Kazdin (2003) *history* and *maturation* are two threats closely related to a study's internal validity. *History* refers to any external events or processes, e.g. in the environment or society, that might influence the result (Kazdin, 2003). *Maturation* refers to processes changing over time. Threats to the internal validity are factors other than the independent variable that could explain the results. Data collection for Paper I-III lasted for about six months for each participant and a number of changes probably occurred during this period, some of which may not have to do with the cancer or aging. This could have influenced the results. Because all participants were aged 65 and above, changes, e.g. in living condition, disease condition/seriousness, loss of spouse/friends, are more likely to occur. This could probably affect the result. Two known explanations for leaving the study were (apart from the deaths of 14 and 24 people respectively in regard to Papers II-III, psychotic, because of brain metastasis, and frailty which led to no further participation in the follow-up study. However, that was to be expected, and one of the study aims to follow up on elderly with cancer over time to identify changes in QoL (Paper II-III).

To follow a specific group of patients over time optimises the potential for revealing the needs for continuing care and rehabilitation. Such design also open up for the possibility of identifying rapid changes in the trajectory of the disease, documenting patterns and being able to make accurate forecasts (Polit and Hungler, 1999) (Paper II-III). A drawback of this study may be that there was no record of the participants' cancer stages, and no link in the measurements to a standard point in treatment cycles or other types of intervention over the first six months. Thus, it may be a shortcoming that cancer stage was not included in the data collection and hence in the analysis. However, the focus of this study was the participant's perception of their life situation, which perhaps is more related to them having cancer and the functional limitations or symptoms related to the cancer, rather than at which stage the disease was or what sort of treatment was offered. This interpretation is supported by the observation that there were no significant differences in QoL, between those who were informed that the cancer disease was over, and those who had been informed that it was not over (Paper II-III).

Collecting data through personal structured interviews may have strengthened the result of the study in more than one respect. The structured interviews were conducted either as 'face-to-face' or over the telephone. The personal structured interview ensured that all questions in the interview schedule were answered (the response rates are higher than would have been the case with postal questionnaires), and there were no internal dropouts in the data collection. Another advantage was that emotive and sensitive questions could be asked and misinterpretations could be checked immediately. The interviewers were able to sense if some questions were particularly difficult for the participant to handle, which was clearly important for people newly diagnosed with cancer and potentially in a sensitive situation (Weisman, 1976). Repeated measures in the shape of personal structured interviews can also offer the possibility of building up a personal relationship between the participant and the interviewer. A possible bias could be that participants respond in a socially desirable way and give more positive answers simply because of this relationship (Bowling, 2002), which could influence the results towards e.g. higher QoL and higher level of hope. This issue cannot be confirmed, however, it needs to be taken into consideration when interpreting the results (Paper I-III).

Testing bias refers to the effects that taking a test one time may have on subsequent presentation performance on the test (Kazdin, 2003). Pre- and post intervention tests might be given to evaluate how much an individual improves or deteriorates over time on a particular measure. In this work, the follow-up design involved repeated data collection three months (Paper II), and six months (Paper III) after diagnosis. The participants were asked question from an identical interview schedule at each three investigation point. One could assume that the participants became familiar with the interview schedule during the 'test-period'. Data collection was performed through personal structured interviews, which meant that the participants did not have the possibility to read the interview schedule before or keep it afterwards and so become familiar with the questions. The data collection method has probably not been a threat to internal validity in this case.

Selection bias refers to systematic differences between groups based on the selection or assignment of participants. Random assignment of participants is the procedure commonly used to minimize the likelihood of selection bias (Kazdin, 2003). The baseline sample (Paper I-III) was chosen from two different procedures. As a part of a pilot-test (the interview schedule and the interview), elderly persons newly diagnosed with cancer were asked by the head nurses in different clinics to participate in the study. This selective procedure was insufficient to recruit enough participants, e.g. the head nurses considerations about whether they were suitable for participating in the study might have influenced the selection. The procedure was changed when 12 participations had been included in the study; thereafter participants were selected from a weekly referral list to the oncology clinic. Apart from being a practical solution this also had the methodological advantage that the author had no influence on which patients were asked to participate in the study (Polit and Hungler, 1999) (Paper I-III). One could argue that the sample might be biased by being restricted to persons referred to an oncology clinic for special assessment and with the aim of receiving therapy. Therefore, one could assume that some groups of elderly persons with cancer were not represented in the study e.g. the frailest. The study, however, provides useful information about elderly persons with cancer referred to an oncology clinic. It may be that the mere fact of being referred to a hospital department in itself could possibly have a positive influence on QoL, since it can be perceived by patients that they receive the best available treatment, which again may lead to higher hope (Paper I-III).

Attrition refers to loss of participants dropping out (e.g. refusal of further participation, death) and may serve as a threat to internal validity (Kazdin, 2003). Attrition is almost unavoidable in studies including follow-up periods, as the remaining subjects cannot be assumed to represent the original sample that was recruited and assigned. Performing follow-up studies 'sample attrition over time' must be taken into consideration, especially if a study include elderly and/or ill people (Bowling, 2002). For that reason 'intention to treat analyses' were performed with comparisons made of those continuing in the study and those lost to it (Paper II-III), in order to assess sample bias (Bowling, 2002). Attrition is a problem in this work, because those who did not continue participation in the follow-up study differed from those who continued by being frailer, resulting in potential biases in the results (Polit and Hungler, 1999). Therefore, it is relevant to consider the influence of the result that 16% (Paper II) and 25% (Paper III) of the original sample was lost to follow-up after three and six months respectively. The analysis of the 'sample attrition

over time' supports that the QoL level (global health status, physical and role function) at baseline for those who did not continue at the follow-ups was significantly lower than for those who continued. In addition, they were significantly more dependent in both IADL and PADL. Thus, there is a strong indication that those who did not continue from baseline were in generally worse condition, and the findings should be interpreted accordingly.

Credibility refers to confidence in the results (true or not) and the conclusions. Recommendations to establish credibility involve activities that make it likely that credible data and interpretations will be produced (Lincoln and Guba, 1985, Polit and Hungler, 1999). Credibility also refers to the believability of the data, which means that the investigation is carried out in such a way that the believability of the finding is enhanced and the steps are taken to demonstrate credibility (Lincoln and Guba, 1985, Polit and Hungler, 1999). To increase credibility, all interviews were conducted in the participants' home to ensure a feeling of safety (Paper IV). All participants had already taken part in one, two, or three structured interviews as participants in the follow-up study, which might have increased their feelings of confidence in the interviewer. In some instances, lack of depth in the interview could arise, because the participants thought they had already recounted their experiences and did not wish to repeat themselves. However, the interviewer strove to make it clear in the beginning of the interview that this specific interview differed from the structured interview. Nevertheless, the character of the interview changed quickly due to the interviewer's attitude, taking part in an active process by probing: e.g. 'Please, tell me more about that...'. By this means, they got closer to the lived experience (Paper IV). The credibility was furthermore increased by using more researchers in the analysis process and by discussing the findings with researchers within other disciplines (Paper IV).

Consistency

Consistency refers to questions of replication, whether a repeated study would yield the same or comparable results every time it is administered to the same or comparable subjects (Lincoln and Guba, 1985). In quantitative studies, consistency may be judged by reliability in qualitative studies by dependability. It is problematical to attain replicability in qualitative research since the reality is multiple, and qualitative research deals with human beings as instruments, changing not only because of error but because of evolving insights and sensitivities (Lincoln and Guba, 1985). Reliability in quantitative studies refer to the instrument regarding the degree of consistency (how the items relate to each other) and refers to whether an instrument measures what it is supposed to measure (Polit and Hungler, 1999, Streiner and Norman, 1989). One way to measure reliability is to use internal consistency, which refers to the extent to which the items are interrelated. The most common method to measure internal consistency is Cronbach's alpha (Cronbach, 1951), which is a function of both the average inter-item correlation and the number of items in a scale. Alpha increases if either of these increases. Theoretically, if no consistency between the items was observed $\alpha=0$, if all items carrying identical information were fully consistent $\alpha=1$ (Cronbach, 1951). Alpha above 0.7 is in general regarded as acceptable, but is often recommended that values above 0.8, and sometimes 0.9, should be used (Fayers and Machin, 2000, Nunnally and Bernstein, 1994, Streiner and Norman, 1989). In this thesis, only tests for internal consistency (Cronbach's alpha) were performed for

each instrument in each paper (Paper I-III). The reliability test of EORTC was considered acceptable ranging from $\alpha=0.77-0.98$, except for emotional function ($\alpha=0.65$) and cognitive function ($\alpha=0.45$). Regarding cognitive function, similar patterns were reported in a Swedish study on elderly with cancer (Thomé et al., 2004). Whether EORTC in relation to 'cognitive function' is suitable for elderly with cancer remains to be further investigated, as this scale has not been calibrated for use in elderly samples. The Katz ADL-Index and ISSI showed acceptable alpha, which may indicate that these instruments are suitable for elderly persons with cancer. In Nowotny's Hope Scale the reliability tests ranged from $\alpha=0.64-0.89$. However, in the subscale 'comes from within' $\alpha=0.30$; 0.26 and 0.20 (Table 6) (Paper I-III) was found, which differs from a Norwegian reliability test-retest at $\alpha=0.80-0.90$ (Rustoen and Moum, 1997). The original internal consistency test was found to be an $\alpha=0.76$ in the original instrument (Nowotny, 1989, Nowotny, 1986). The 'comes from within' is an expression of trust developed within oneself, and is an inner readiness that is available for use when needed. The reason for the low alpha values in 'comes from within' may be too few items; it consists of three questions whereas as a minimum of four to six items are recommended to represent a proposed consistency. It could be disputed whether the questions are in accordance with Nowotny's stated intentions, since they may not be coherent. Translation of the instrument (according to accepted rules) (Streiner and Norman, 1989) was checked several times with one more translator. No explanation was found. The test result may lead to a critical reflection on the use of the scale. It is likely that Nowotny tried to capture too many aspects of hope in her definition and that the aspects that did not correlate with one another. Psychometric tests on NHS are recommended to calibrate the instrument for use among elderly people.

Dependability refers to the replicability of the study and the stability of data over time. According to Lincoln and Guba (1985) there is no credibility without dependability, and they suggested that a thorough description of credibility is needed to establish dependability. To let two researchers deal with the qualitative interviews separately (Paper IV) and to let an external reviewer scrutinise the data separately is to establish dependability (Lincoln and Guba, 1985). In the analysis process (Paper IV), the author and another researcher strove to avoid the risk of their pre-understanding influencing the analysis, being aware that some parts of the pre-understanding are subconscious and therefore difficult to reach (Dahlberg et al., 2001). Nevertheless, it is not possible to perform a phenomenological study without 'knowing something' about the phenomenon (Morse et al., 2002, Speziale and Carpenter, 2003), and in that sense to strive for bracketing was a two-edged sword. Bracketing meant putting the authors' knowledge aside to see the interviews with fresh eyes and continuously discussing the professional experience; conversely, the authors' as above experience functioned as a guide to keeping the phenomenon in focus by being aware and constantly asking analytic questions 'what is the lived experience of...'. Giorgi's analysis steps were followed rigorously, and findings were discussed with researchers within other disciplines to increase the dependability (Paper IV). To further strengthen the dependability, the analysis was performed concurrently and discussed by the first author and other researchers, who had different degrees of closeness to the interviews, which may have given a more comprehensive interpretation and description of the phenomenon (Paper IV).

Construct validity

Refers to the degree to which an instrument or measuring procedure measures what it is supposed to measure and whether that can be responsible for the changes that have been found (Kazdin, 2003). Construct validity refers to whether the variable under study is itself responsible for change or whether other plausible factors can account for the effect, i.e. to what degree the instrument measures the construct (Kazdin, 2003). Threats to construct validity refer to features associated with the intervention that interfere with the interpretation. In this thesis, distinct inclusion criteria were used and every participant was invited to participate by letter and subsequently contacted by the author. However, in relation to the follow-up measurements (three and six months after) participants were contacted by the author by phone, which may increase the risk of attention influencing the result due to the personal relationship developed. Several features within the experiment can interfere with the interpretation of the results. These are often referred to as confounders. Thus, construct validity can be explained as the risk of an instrument measuring other phenomena than that intended. Furthermore confounding variables may interfere with the interpretation of the results. Since age and gender are usually known to be confounding variables, these two variables were controlled for in all multiple regression analyses (Paper I-III).

Neutrality

Neutrality refers to the degree to which the findings are a result of the participants' and not the researchers' biases, interests and perspectives (Lincoln and Guba, 1985). The neutrality of quantitative studies is identified as objectivity and in qualitative studies as confirmability.

Objectivity in quantitative research refers to the extent to which two independent researchers would arrive at similar judgments or conclusions, i.e. judgments not biased by personal values or beliefs (Polit and Hungler, 1999). Results from EORTC were compared with two earlier population based studies (using EORTC QLQ-C30) performed respectively in Denmark (Klee et al., 1997) and in Sweden (Michelson et al., 2000), differences of more than 10 units could be identified in similar age groups (King, 1996). Hence, elderly persons newly diagnosed with cancer in this work had a clinically important lower QoL in physical and role functioning compared to the population studies. This finding was consistent with a Swedish cross-sectional study also using EORTC (Thomé et al., 2004) which strengthens the use of EORTC in this thesis.

Confirmability refers to the objectivity or neutrality of the data (Lincoln and Guba, 1985). Confirmability means obtaining direct, and often repeated, affirmations of what the researcher has heard, seen or experienced with respect to the phenomenon under study (Lincoln and Guba, 1985). Moreover, it refers to the way researchers document the confirmability of the findings, which is a recording of activities over time that another individual can follow (Lincoln and Guba, 1985). To achieve confirmability, the author and three other researchers discussed the findings with one another continuously during the analysis process to ensure that the findings were grounded in the texts (Paper IV). Moreover, confirmability was obtained in an interaction between the texts presenting the findings and the quotations illustrating them (Paper IV).

Statistical conclusion validity

Statistical conclusion validity refers to the extent to which a statistical relationship can be proven significant. Furthermore, it refers to aspects that may affect the quantitative evaluation of the study and that could lead to a misleading or false conclusion (Kazdin, 2003). This type of validity is often viewed and interpreted from two perspectives: the risk of Type I error (α) and the risk of Type II error (β). The calculations used in these studies were based on a power=0.90 (90%) with a significance level of $P=0.05$ (5%) for detecting statistically significant changes in QoL over time (Paper I-III).

Type I error is the risk of rejecting the null hypothesis when it is in fact true, i.e. the risk that the researcher concludes that a significant difference exists when in fact there is none. In this thesis, multiple comparisons were performed with a reduced P-value calculated to reduce the risk of mass significance (Altman, 1991, Bland and Altman, 1995) (Paper I & III). A reduced P-value ($P<0.013$) was used due to multiple comparisons, across four age groups (Paper I). A reduced P-value ($P<0.017$) was used due to multiple comparisons across different investigations point (baseline, three-month and six-month) (Paper III). Otherwise the P-value was set to $P=0.05$ (Papers I-III). Altman (1991) does not recommend a large number of group comparisons (no more than four to five) because poorly specified research objectives may then be found.

Type II error is the risk of not rejecting the null hypothesis when it is false, which means that the researcher concludes that there is no relationship when in fact there is one. The risk of type II error depends on sample size or the power to detect differences between the size and the sample (Altman, 1991). Power analysis was calculated on the sample size in Paper I before the investigation to reduce the risk of type II error. Power was calculated by $1-\beta$ (Altman, 1991). The risk of insufficient power was considered low in Papers I-III. Calculation of necessary sample size, with allowance for a dropout rate of 25% between baseline and follow-up at three months, showed that inclusion of 100 patients at baseline would give a power of 93% to detect a clinically relevant difference of 10 units in EORTC from baseline to three months. By choosing an acceptable sample size, it may be possible to find 'true' differences when comparing groups. The high number of participants leaving the follow-up study during the first six months obviously decreased the sample size (by 25%) and the power of the statistically tests was thus reduced, whereby some weaker, but practically important, risk factors may have been overlooked. However, power showed that sample size calculation was significant.

Clinical significance

Clinical significance refers to the clinical value of the effect of an intervention, that is, whether it makes any 'real' difference to the participants in their everyday life (Kazdin, 2003). The fact that a change is statistically significant does not necessarily imply that it also has clinical significance (Fayers et al., 2001) and is meaningful to the participant. King (1996) has reported that changes in EORTC QLQ-C30 scores of 10 units or more should be considered clinically significant, independent of any statistical significances identified. In this thesis, the recommendation of King (1996) provided guidance in two respects. Firstly, to interpret e.g. differences in global QoL over time, a difference of 10 units was interpreted as relatively high and of clinical relevance (Paper II-III). Secondly,

new variables were created to identify those experiencing deterioration in QoL of 10 units or more (Paper II-III).

Applicability

Applicability refers to external validity in quantitative studies and transferability in qualitative studies. It refers to the probability that the study findings have meaning to others in similar situations or context (Lincoln and Guba, 1985, Speziale and Carpenter, 2003). *External validity* refers to the extent to which findings can be generalised, beyond the sample, the settings and the conditions in which the study was carried out (Kazdin, 2003). The sample investigated in this study was selected by simple random sampling (in the second procedure) (Polit and Hungler, 1999) which may have strengthened the external validity due to minimising the influence of systematic and personal biases. Nonetheless, the inclusion and exclusion criteria may be questioned as a threat against external validity. Including four different cancer diagnoses may be a shortcoming, because each diagnosis has different trajectories and different health care-related problems. Conversely, mixed groups provide knowledge about those diagnoses that are the most prevalent among elderly people. There was an over-representation of women (73.3%) at baseline (Paper I) due to the over-representation of women-related cancers (breast and gynaecological). Previously, elderly women with cancer have been shown to have poorer QoL compared to men, and also poorer QoL compared to women without cancer (Thomé et al., 2004, Thomé and Hallberg, 2004). Thus, the result from this thesis may be biased towards elderly persons with cancer with low QoL than if the sample represented gender equally.

Some groups of elderly with cancer were probably not represented in the study e.g. the frailest group, those in hospital, those in sheltered house and those with limited understanding of the Danish language, which may be perceived as a disadvantage. The disadvantages are that the sample was narrowly defined as only those who were referred to the oncology clinic for special assessment, and not for those of the elderly who were informed about their cancer, but not offered any treatment or supportive care from a specialist clinic. In addition, those 160 deceased 'at the referral list' and those who refused to participate, may be the frailest. Persons with lung cancer are considered the most vulnerable group in the total sample and were also identified as associated with low QoL (Paper I). Consequently, the interpretation and generalisation of the results should be done carefully. Further studies may benefit from focusing on different diagnosis groups to obtain more specific knowledge about trajectories within different diagnoses. Thus, the studies can be generalised to elderly persons aged 65+ years in Denmark, and could be generalised to similar settings inside and outside this context.

Transferability refers to the extent to which the findings are referable, can be generalised or transformed to other groups or settings (Lincoln and Guba, 1985, Polit and Hungler, 1999). Moreover, transferability refers to the probability that the study findings have meaning to others in similar situation (Lincoln and Guba, 1985). Within the phenomenological tradition, the number of participants is not a question of size, instead, a question of all aspects of the phenomenon being represented with variation by the participants (Mayan, 2001, Morse et al., 2002). When no more essences of the phenomenon showed up in the interviews, it was taken as a sign of saturation (Paper IV).

Different diagnosis groups, different types and combinations of cancer treatment, and participants interviewed at different stages of the illness trajectory ensured sufficient data to account for variation in the phenomenon. This indicates that the findings of this study can be transferred to other elderly persons with cancer (Paper IV).

General discussion of the findings

This work advances our understanding of QoL and its change over the first six months, in elderly persons newly diagnosed with cancer. To the author's knowledge, this is the first study that has followed elderly persons in their early period following a diagnosis of cancer, and highlights some important results which need to be discussed.

Quality of life

The focus of this thesis was to study QoL in elderly persons with cancer, through several factors, focusing on how it changes over time. Furthermore, the emphasis was to focus on low QoL and its deterioration from a multidimensional viewpoint. QoL was measured by EORTC, an HRQoL instrument where a person's perceptions of health status and aspects of life are considered in relation to expectations of normal living (Harrison et al., 1996). EORTC cover aspects such as general health, physical functioning, physical symptoms, emotional functioning and cognitive function (Fayers and Machin, 2000). QoL in elderly persons with cancer did not change significantly during the first six months (Paper I-III). However, it is important to remember that the score of QoL in any each of the three scales in EORTC was compared with results from Scandinavian population studies, and the elderly persons from the work described in this thesis had poorer QoL compared to those included in the population studies (Hjermstad et al., 1998, Klee et al., 1997, Michelson et al., 2000). This is consistent with a Swedish study which compared older persons (75+ years) with and without cancer, and found that the cancer group had poorer QoL in different domains of EORTC (Thomé et al., 2004). EORTC QOL-C30 was specifically developed to be used in follow-up studies, and has been proven to be a reliable instrument, especially to identify changes in QoL over time, and to be sufficiently sensitive to detect important dimensions in QoL in persons with cancer (Fayers et al., 2001). There being no significant changes during the first three months were a surprising result (Paper II). One possible explanation may be that the EORTC instrument is not capable of measuring over time the special issues influencing QoL of elderly people with cancer, such as cognitive difficulties, decreased social network and function, financial difficulties or reduced function in daily living.

To capture changes in QoL that may occur shortly after diagnosis may also be too blunt a measure. However, several explanations may be possible in interpreting the result. Perhaps the elderly received sufficient support to be able to cope successfully with their new situation. Perhaps long life experiences had strengthened their ability to draw upon ample capacity to cope with a cancer diagnosis and to maintain their QoL in the beginning of the disease trajectory. The participants who remained in the follow-up study from baseline to six-month follow-up may not be those who were the frailest among the elderly with cancer. One possible explanation is that the frailest were not referred to the oncology clinic. The level of global QoL was at baseline median 75.00 (IQR 33-33) and six months after 66.67 (IQR 33.33) (Paper III), which according to King (1996) is classified to be a

high score for Global QoL. The findings reported in Paper IV support this interpretation. Getting cancer implies losing control over life; however, one way to manage this 'lost-control' was to accept the changed situation. Seemingly, advanced age helped them to remind themselves that for older people getting cancer is different from if they were diagnosed when young. The way to manage the changed situation can be understood from the 'selection' part in the SOC-model: the participants strove to concentrate on what was important right now expressed as '*enjoying every single day right now*', and get back in control.

In a study by Rustoen (2000) QoL was found stable during the first three months for newly diagnosed cancer patients with a maximum age of 78 years, whereas issues related to family matters were not stable (Rustoen et al., 2000). Perhaps it is less challenging for the elderly to accept their new condition, and perhaps they are more ready to deal with the finite nature of life compared with younger persons. This is supported in findings from Paper III where emotional function decreased significantly over the first six months. One possible explanation could be that for some the onset of cancer became a confirmation of being elderly, and offered a new outlook, which made it easier to accept the disease. Another possible explanation could be that the participant's personality and ability to manage life with cancer in a new and uncertain situation were strong. A third explanation may be that these persons changed their perspective of QoL after being diagnosed with cancer; perhaps they learned to be content with the actual situation and adapted to living with the disease as a part of the SOC model. The findings indicate that the elderly with cancer perhaps handle the emotional stress caused by the diagnosis differently from younger persons with cancer. However, remembering that the QoL of elderly people with cancer in this study was lower compared to those without cancer, health care professionals still need to identify how best to maintain QoL, especially for those who have particular problems mobilising such capacities.

Although QoL in the total sample remained stable, some of the individuals developed significant weakness over the first six months, which underlines the need for recognition by health care professionals immediately on diagnosis in order to counteract the serious reduction in QoL that could occur in the early stages. The sample was divided into those with deteriorated (30.7%) (with 10 points difference) QoL and those in whom it was stable (Paper III); an interesting pattern that emerged could inform clinical practice. Those with deteriorated QoL had a significantly higher global QoL score at baseline (median 88.33, IQR 25.00) than those who remained stable in QoL (median 66.67, IQR 25.00). This finding indicates that one cannot assume that those who score relatively high global QoL at time of diagnosis necessarily are those who cope best with the changed situation. Furthermore, those who deteriorated had a median score at baseline at 88.33 (IQR 25.00) and, six months after, a median score at 50.00, IQR 33.33). A difference in global QoL of 10 units has clinical significance according to King (1996), and a median difference at 38.33 is seriously high. The global QoL questions represent an overall feeling about oneself, life in general and health; a feeling that significantly changed towards the negative. At least two conditions may be important when drawing clinical consequences of the findings. The fact that about 70% of those who deteriorated in QoL lived with the knowledge that their cancer had not come to an end, may contribute to this condition. The seriousness of the disease cannot be understood in the results from the symptom scale, since symptom complaints were limited, except for fatigue and pain. However, the

consequences of the seriousness of the disease were seen in the interviews (Paper IV). Awareness of the diagnosis evoked feelings that life was out of control, and information from the physician seemed to be decisive in the degree of lost control, or for recapturing control. This ought to be the basis of guidance in clinical practice when meeting elderly persons newly diagnosed with cancer. Moreover, follow-up studies focusing on QoL of elderly people with cancer are, to the author's knowledge, scarce, and more studies are needed to verify which QoL instrument is the most suitable for this specific patient group.

Health complaints

Fatigue turned out to be more than a feeling of being tired. Fatigue was found not only to be the most dominating symptom and the most frequent complaint at baseline, three and six months after (Paper I-III), but also experienced as the dominating and most distressing symptom, with a tremendous impact on everyday life leading to bodily limitations (Paper IV). In this thesis, fatigue was not investigated as a dependent variable, neither as a separate variable in the logistic regression analyses to identify the relation between fatigue and QoL. Fatigue did not change significantly over time in this study, yet, it was still higher at baseline (median score 47.3 (SD 14.47) compared to healthy Danish elderly people (aged 71-75, mean 30.2 (SD 26.0) (Klee et al., 1997) (Paper I). Such a comparison emphasizes the magnitude of the problem of fatigue in the elderly with cancer but it is also confirmed by the interviews. Fatigue is regarded as one of the most distressing symptoms in patients with cancer; however, it is scarcely investigated among the elderly with cancer. However, fatigue was found to be a precursor for loss of function in elderly with cancer (n=907; aged 65+) (Given et al., 2000), and Avlund (2002) proved that those elderly (n=510 and 429 (5 years later); aged 75+) who felt tired were more at risk of being hospitalised and of needing home help five years after. The result indicates that it is important to take these early signs of fatigue serious as these people are at a higher risk than others of becoming dependent on help. The specific aetiology of cancer or treatment-induced fatigue is still poorly understood, and therefore the correct management of fatigue is far from clear. Caring for the elderly with cancer suffering from fatigue it is important to pay attention to them because it may well be the first sign of both dependency and frailty. Fatigue in old people presents a significant risk factor for functional disabilities and in addition can be a dominating symptom disruption daily activity. Health care professionals need to include routines for assessment and evaluation of cancer-related fatigue (Ahlberg et al., 2005). The findings in this work prove that fatigue becomes a source of limitations in everyday life and a reminder of being old (Paper IV). On the other hand, the participants also showed that elderly were able to use the SOC strategy, both in selection and compensation. Selection occurred when participants strove to accept fatigue and the limited resources it brings which mean that they can no longer do certain things. Compensation meant regulating everyday life by taking extra naps e.g. before an activity such as going out. Patients may benefit from health-care professionals acquiring a complete picture of fatigue in the elderly through a systematic assessment where, for example, functional limitations related to fatigue can be determined. More research is required to investigate fatigue (based on a more targeted fatigue instrument) in the elderly with cancer and preferably through longitudinal studies to identify the development of fatigue and to plan for suitable individual intervention.

Caring for the elderly taking the individual into account is important regarding not only age, but also type of disease. Lung cancer was significantly associated with low QoL, and similar findings have been reported in other studies (Di Maio and Perrone, 2003, O'Driscoll et al., 1999) Lung cancer holds a unique position among solid tumours, because at the time of diagnosis the disease is more advanced and the median survival relatively short (Grunberg and Bibawi, 2000). This may also be the reason why it was primarily those with lung cancer who did not continue participation in the follow-up study (n=14 died out of 25) indicating that they were the most vulnerable group in the sample, also suffering from a number of symptoms. Lung cancer has been studied under a range of parameters, from newly diagnosed (Hill et al., 2003) to those undergoing palliative care (O'Driscoll et al., 1999), different types of lung cancers (Kuo and Ma, 2002, Walker, 2003) the elderly with lung cancer (Balducci, 2003, Gift et al., 2004, Gift et al., 2003, Hurria and Kris, 2003, Peake et al., 2003) and from the perspective of gender (Sarna et al., 2005). Hill (2003) found that newly diagnosed patients with lung cancer (median age 68, range 36-84) were specifically worried about treatment and loss of independence; and Hill also found that fewer than 30% felt that they had been given opportunity to discuss their worries with the professionals (Hill et al., 2003). The fact that patients with inoperable lung cancer suffer from severe symptoms compared with other groups of cancer patients has also been emphasised by Tishelman (2005). Tishelman et al (2005) identified breathing, pain and fatigue as the symptoms associated with most distress (n=400), and the authors recommend to foster a preventive paradigm in palliative care of patients with lung cancer to minimize the distress caused by the symptoms. However, it is important to remember that the trajectory of lung cancer varies according to the type of lung cancer and the stage reached when diagnosed. Lung cancer diagnosis and treatment often produce stress as a consequence of the actual symptoms of the disease. Systematic ongoing nursing assessment of symptoms may be the first step in enhancing interventions to decrease distress. Health care professionals may not necessarily need to focus on diagnoses, but on the individual. However, this study emphasises the clinical importance of being aware of specific diagnosis-related problems and that elderly people newly diagnosed with lung cancer are in a particularly vulnerable position, and need special attention in regard to clinical conditions to compensate for their grave situation in relation to QoL.

Dependence

The ability to perform the activities of independent daily living changed significantly over time and influenced it negatively. Dependency was shown to be significantly related to low and diminished QoL, and to dominate the experience of being old and living with cancer (Paper I-IV). In this thesis, low capacity for IADL was found to be associated with low QoL at baseline and again at three-month follow-up (Paper I-II). Furthermore, dependency in PADL at baseline was related to deteriorate QoL (Paper II). In addition, increasing need in IADL developed significantly from baseline to six-month follow-up in those who diminished in QoL (Paper III). Furthermore, the need for more help in daily living at baseline was a predictor for decreased QoL at six-month follow-up (Paper III). The findings in this thesis about QoL and need for more help in daily living corresponds to the findings in an earlier study by Stenzelius (2005) who showed that those needing help in IADL and PADL (aged 75-105, n= 4277) had significantly lower QoL compared to those who were independent. Declining functional ability may be related to lost

autonomy and lowered self-esteem, and may in addition be viewed as a natural part of the aging process. Yet, it is essential to draw attention to the fact that dependence influences QoL negatively. Irrespective of what kind of help they received when disabilities reach the point where people are not fully able to care for themselves, dependence and a reduced QoL are significant causes for concern. However, the issue of dependence vs. independence when in need of IADL and PADL is most likely a subjective experience. In this thesis, the experience of being dependent was described in terms of fear of being a burden to others and the feeling of losing identity due to dependence (Paper IV). Dependence related to a person's identity seems essential which was also found in a phenomenological/hermeneutic study. Strandberg (2002) found that being dependent meant an existential struggle about value as a human being, as identity is built upon being strong and able to manage oneself. Fear of being a burden to others has been pointed out as a significant issue for cancer patients in general (Cheville, 2005, Ussher et al., 2005) and especially for terminally ill persons (Wilson et al., 2005). The importance of this issues has also been raised by Roland (1990) who further emphasises that those who provide help need to be aware of the reactions of the person who receive it, and furthermore that the person needing help has to accept certain types of help and support without feeling guilty, losing self-esteem, or even become passive.

Dependence on the health care system turned out to be a predictor for deteriorated QoL (Paper III). Those in contact with health-care system seemed to be more frail (Paper III). The result indicates that the health of the more frail participants was more affected than that of the others by the cancer or other health problems. This issue also came up in the interviews (Paper IV). One area that was experienced to be out of the control of the individual was that the illness led to contact with the health-care system (Paper IV). Getting cancer was identical with the experience of being a patient, which meant that the body, disease and treatment took over and controlled life, as opposed to controlling one's own life (Paper IV). Recently it has been reported that older people (aged 75; n=28) experienced difficulties in coping and adapting to having no influence over the decision about receiving public-funded home help (Janlöv et al., 2006). The result from Janlöv may be useful in interpretation the result from this thesis. Having contact with District Nurse and/or the health care system in other respects may be viewed as consequence of being a patient and the situation somehow being out of the individual's control. Understanding the experience of living with cancer and the impact of being in contact with the health care system may unavoidably lead to areas where the elderly can retain control in life. One response should be to involve the elderly in decision-making regarding their contact with the health care system, which may strengthen their feeling of control. To involve them in the decision-making process may strengthen the SOC, which means that they are expected to make use of the adaptation process. Thus, attention to ADL capacity in the elderly with cancer seems vital to identifying those who experience limitations. When considering cancer in the elderly, other problems are also prevalent, and a narrow perspective on the cancer may be detrimental to the older person's QoL. Health care professionals need to pay special attention to those who at the time of diagnosis are already dependent, since it was found to be a predictor for deteriorated QoL within the first six months. Comprehensive Geriatric Assessment (CGA) has been recommended to identify vulnerable individuals among elderly with cancer in order to optimize adjusted care (Chen et al., 2004). In addition, CGA has proved to be a sound procedure to recognize the heterogeneity of the elderly population and focus their care

plans accordingly (Reuben, 1997). Such assessment may lead to a deeper understanding of how dependence contributes to low and deteriorated QoL in the individual, and to a more accurate intervention for the individual.

Another finding may contribute to further understanding of the elderly with cancer being dependent. 'Getting help from adult children' was significantly associated with low QoL at baseline (Paper I); in addition, it also increased significantly from baseline following the first six months (Paper III). The fact that adult children provide help to their ill parent does not say anything about the quality of help provided, neither that the elderly appreciated their contribution. To rely on help from adult children may not only be related to receiving help, but also to changing roles from helping ones own children, and now to getting help in turn from them as adults. This is consistent with the interviews revealing the family balance to be disturbed and the elderly fearing becoming a burden to their family members (Paper IV). Fear of being a burden on e.g. adult children added to the difficulties of coping with the changed situation by wishing to protect one's next of kin.

Financial resources

Limited financial resources and a decline in economic capacity had a negative effect on QoL in the elderly with cancer. Association between 'having no other incomes than retirement pension' and perceived 'reduced economic ability due to the cancer disease' and low QoL were found in Papers I and II. In total 27.7%, of the participants had no income other than their retirement pension (Paper I). Furthermore, 22.4% perceived reduced economic ability due to the cancer three months after time of diagnosis (Paper II); however, the result may be regarded as somewhat unspecific, which is also shown in the relatively large CI (1.029-20.100) from the regression analysis. The relation between poor financial resources and low QoL corresponds to the findings in earlier studies on older people with cancer (McGill and Paul, 1993, Thomé and Hallberg, 2004). In Denmark, assistance from the elaborate public health-care system is free of charge for any citizen. Consequently, the result cannot refer to economic burdens due to contact with the public health-care system as such. More likely, the financial burdens experienced are due to extra costs such as transport by taxi to and from chemotherapy in outpatient clinics; expenses for complementary and extra medicine, increased practical assistance at home, care items, and consulting psychologists outside the public system. Another explanation is that the limited financial resources of the elderly with cancer may lead to decreased ability to participate in social activities, low health status, poor emotional well-being and loneliness (Posborg, 2003), and thus probably lead to low QoL. Accordingly, health-care professionals may be advised whenever possible to avoid financially burdening patients whose finances are strained, as this may further diminish QoL. In addition, steps to improve their financial situation may be helpful, for instance informing them where to obtain economic support. Thus, health-care staff should perhaps assume an active role in addressing concerns for financial security. It seems essential that nursing staff feel comfortable in allowing themselves to discuss financial issues with the patient in order for them to provide appropriate guidance and counselling. In addition, future research concerning financial issues may be needed to recommend appropriate actions related to the added financial burdens of elderly persons with cancer.

Social network and support

Charmaz (1991) has pointed to that living with cancer occurs within a personal and social context, and that problems of living with cancer fall squarely on the ill person and, by extension, on their family (Charmaz, 1991). This was also the case in this thesis. The structure within the family seemed to be changed and the reciprocal relationships were affected because a family member was diagnosed with cancer.

In this thesis, social network and support was measured by the shortened version of ISSI (Unden and Orth-Gomer, 1989). In order not to bother newly diagnosed elderly people with cancer with too many sensitive/emotional questions the two subscales (ADSI and ADAT) about the evaluation of the social network and support (25 questions in total) were removed from the questionnaire. It means that this study solely provide knowledge about the quantitative part of the social network and support. However, a significant difference in social network (AVSI) was found from baseline and following the first three months (Paper II). Several interpretations may be reasonable. It is perhaps not an expression of reduced social network, but rather that the elderly actually needed more support from the network, or at least more support than the network was able to or prepared to provide. This is not unusual in persons diagnosed with cancer, which also has been suggested by (Rowland, 1990). Perhaps, it is an expression of the vulnerability the person experiences in relation to social network, and an example of the changed structure and function of the network for the participant (Due et al., 1999). From the interviews came the finding that family balance was disturbed due to the cancer diagnosis. It meant that social relations were both encouraging to the individual and at the same time increased vulnerability (Paper IV). According to Meleis (2000) transition requires a person to incorporate new knowledge, to change behaviour and therefore to alter the definition of him or her self in a social context. Health-care professionals cannot assume the social network necessarily to be something that is experienced as encouraging for the patient (Rowland, 1990, Ussher et al., 2005, Wilson et al., 2005). The elderly strive to balance their own needs and burdens with the needs and uncertainties of family members and not to put additional burdens on them. In meeting the elderly with cancer it is essential to be aware of these conflicting needs i.e. not add to the burden of others and at the same time lean on others for support yet not add to their burden. Perhaps the elderly person may need support to allow others into their life world. One way to support those in need of help and make their 'dependence' more manageable may perhaps be by including them in choices about the help they receive and from whom.

It is notable that, in some cases, grandchildren were involved in providing help to their grandparent diagnosed with cancer (Paper III). The strength of this result is found in the interviews where the elderly expressed special attention to grandchildren and gave them high priority in different matters (Paper IV). Concerns were revealed as not involving them in the illness, sparing them and taking care of them. The concerns were managed in different ways, by either not telling anything to the grandchildren or adopting an open attitude to the illness and cancer treatment, and discussing issues with a grandchild (Paper IV). A number of issues need to be taken into account when interpreting the result. It indicates that the structure of the family changed. This may in fact be a natural part of the life-cycle, that those growing older necessarily take on more and more responsibility. From that point of view, it is not surprising that the younger generation took over and supported the elderly person. However, it may not necessarily be the case in the Nordic

countries, where to a greater extent the public state takes increasing responsibility. Thus far, knowledge about grandchildren as caregivers is scarce. Nevertheless, they may play an increasingly significant role. Drageset (2004) found in a Norwegian study that the elderly in nursing homes (aged 65-101) who were often in contact with grandchildren reported a significantly lower level of loneliness than those with less contact. By tradition, there has been focus in social science on the spouse and children, which might stem from the judicial importance of these next of kin. Grandchildren take part in the life situation of the elderly and it seems essential in caring for the elderly with cancer to enlarge the perspective of their social network to include grandchildren. They represent a younger group of the social network/of the family, and may have sparse experiences with illness and possible impacts on an ill person or themselves. Yet, knowledge about grandchildren is limited, and future research is needed to investigate issues regarding them as younger caregivers. Unfortunately, this thesis cannot contribute information about the kind of support grandchildren rendered, nor how they experienced the care-giving situation. Therefore, it seems essential that future research should explore issues surrounding grandchildren as caregivers to the elderly with cancer.

Hope

The theoretical approach to hope in this thesis was not only related to the future, but also to new goals and strategy for life, and/or feelings of safety and comfort (Nowotny, 1986). Hope stood out as a significant factor in living with cancer in old age. The findings in this thesis showed that hope was essential for the elderly newly diagnosed with cancer (Paper I-IV). Low levels of hope were associated with low levels of QoL at baseline and at three-month follow-up (Paper I-II). In addition, a low level of hope was found to be a predictor of diminished QoL over the first six months (Paper III). Furthermore, the total hope score decreased significantly over the first six months, though still classified as moderately hopeful according to Nowotny (1986). Those who experienced diminished hope may perhaps be the most vulnerable of the participants.

The way a person copes with stressful events such as illness is related to a process influenced by the personality, the situation and the environment, and is characterised as a stable capacity (Rustoen, 1995). According to Rustoen (1995) hope can be regarded as a component in the individual's ability to cope with stress in a life-threatening situation. Interpretation of the result from this thesis may though need to be done with caution for at least two reasons. Firstly, the relation between QoL and hope is uncertain (Rustoen, 1995). Secondly, the reliability test of the subscale depicted 'comes from within' was low in all three measurements ($\alpha=0.30-0.20$) (Paper I-III). However, the results from the qualitative study confirm that the existential dimension, such as hope in elderly newly diagnosed with cancer, is essential (Paper IV).

According to Charmaz (1991) illness forces a new awareness of relationship to time. This could also be seen in the essence 'consciousness about dying and death through illness experience' which was identified in the qualitative study (Paper IV). When illness became inevitable more time was spend on reflecting on one's life, on living with cancer and on death, which according to Jasper (1949/1953) is when a person faces what he calls 'limit situations' that every human being has to face. Further, Jasper stated that people are always in situations and while, to some extent they can influence the situation they are in,

there are some situations, which carry inevitability. Such situations are e.g. that death is a part of every human being and for some a cancer diagnosis is an inevitable reality. Thus, according to Jasper (1949/1953), as well as to Baltes and Baltes (1993), every person has the possibility of influencing on own situation. In this study, elderly people with cancer had to face the possibility that they might die from it and not see for example the following spring. On the other hand, curiosity about life, still having goals, still hoping that the physician might bring good messages, became the optimisation strategy. Despite thoughts about life and death, they still managed to enjoy life, which perhaps is the core of the SOC model that the elderly to some extent were able to strengthen their belief in handling difficulties and to set up new goals despite the many uncertainties.

Decreased hope may perhaps be one of the most vulnerable situations to experience as a human being. Decreased hope may be understood from the perspective of the seriousness of cancer. The answers to the question 'Has your doctor told you that the disease is not over?' changed significantly over time, in particular those with deteriorated in QoL (Paper III). In this case, Kleinman (1988) is helpful. Truth about a cancer is not based solely on what the physicians say or see. A person's perception of the disease, how it is experienced and interpreted by the individual is of importance (Kleinman, 1988). The participant's perspective that hope was threatened is depicted in essence as: 'Illness means losing control' (Paper IV). This signifies that the disease represents uncertainty and the sense of security has been seriously shaken. If hope is reduced or missing, the elderly person is likely to be vulnerable. In the literature, hope has been described as an important part of a person's perception of the actual situation and of their ability to handle it (Herth and Cutcliffe, 2002). Unfortunately, this seemingly was not the case in all participants in this thesis. To obtain a deeper understanding of hope in the elderly with cancer, it is necessary to consider the result of the different subscales. Despite the relevance of existential issues related to living with cancer it has been investigated little, nor has it been included in the EORTC QLQ-C30. Existential issues have primarily been investigated in relation to palliative or end-of-life care (Halldorsdottir and Hamrin, 1996, Landmark et al., 2001). Women had significantly more 'spiritual belief' compared to men, and those stable in QoL had more 'spiritual belief' compared to those with deteriorated QoL (Paper III). This adds to the understanding that spiritual belief and -issues may be significant regarding hope and how to cope with a life-threatening illness. However, much still has to be learned from that perspective. The importance of spiritual matters has been raised previously. Halstead (2001) found in a qualitative study (10 women diagnosed with cancer, aged 45-70) that a diagnosis of cancer threatened the meaning of the women's life, resulting in a sense of disintegration. They reintegrated over time, and the spiritual growth became an important factor in that contribution. The findings in this thesis indicate the need for health care professionals to focus on hope as an important factor influencing QoL, but also the need to focus on elderly person's capacity to cope with cancer in late life, and to strengthen their belief in handling difficulties. However, this area, including the influence of spirituality, should be investigated further. The power of hope cannot be estimated in the care of elderly with cancer.

CONCLUSIONS AND CLINICAL IMPLICATIONS

The findings of this thesis showed that there were no significant differences in QoL in the four different age groups, and the situation of elderly persons with cancer cannot be understood as simply a function of chronological age, but as an individual process with certain individual characteristics of events and situations. The overall QoL in elderly persons with cancer did not improve or deteriorate significantly from baseline to three months after. Neither did QoL change from baseline to six months after except from improvement in nausea/vomiting and in emotional function, and the majority of elderly persons with cancer showed an ability to adjust to the new condition. However, about one third had deteriorated in QoL by the significant ≥ 10 units at six-month follow-up, and they represent the most vulnerable group of the elderly newly diagnosed with cancer. The most vulnerable stood out as those with advanced disease and decreased hope, those with increased need of both formal and informal assistance, those with reduced financial means and those with lung cancer. Thus, they need specific attention from health care professionals.

The results highlight the importance of being aware of factors contributing to low QoL with the aim of improving QoL. Dependency affects QoL negatively, and highlights the necessity for health care professionals to assess ADL in elderly persons with cancer in clinical practice, because such knowledge can lead to precise intervention. Contact with DN predicted deteriorated QoL over the first six months and was interpreted as an expression of the seriousness of cancer disease at time of diagnosis, and as an expression of having lost control over own situation. Limited financial resources and reduced economic ability due to cancer disease seems to affect QoL negatively in elderly with cancer, and knowledge about the financial impact on QoL increase the need for appropriate counselling based on more specific documented knowledge. Health care professionals may assume an active role in addressing concerns for financial security, and discuss financial issues with the elderly.

In clinical practice, specific attention should be paid to the groups of elderly persons made most vulnerable by certain types of cancer: those with lung cancer and advanced disease. The size of social network and support provided by the network did not change significantly. However, grandchildren increasingly provided help to their ill grandparents, and this thesis emphasise health care professionals to enlarge understanding of who the network consist of and perhaps take on the responsibility to support grandchildren as caregivers. The reciprocal relation between QoL and hope is still unclear. Though, low level of hope were significantly related to low level of QoL or predicting deteriorated QoL over the first six months. The capacity to cope with cancer in late life seems to be an essential component in hope in the elderly with cancer; thus to strengthen hope is essential. In addition, it seems significant that health care professionals take time to listen to and counsel the elderly regarding their concerns. Furthermore, health care professionals need to identify what capacities the elderly with cancer possess to enable them to make best use of the developmental regulatory process (SOC). This is perhaps the key condition for enabling them to remain actively involved in everyday life.

The lived experience of getting cancer in old age meant that life was interrupted, and that the illness became a turning point marking old age. It meant that the participants changed

their perception upon themselves in several matters. The illness represented an uncertainty that led to a feeling of having lost control. Getting cancer meant being forced into the role of a patient with contact to health-care system, bodily limitations, disease, and treatment seemingly taking over control. The balance within the family was disturbed, and the participants registered that family members were affected and it became a burden on the elderly to balance their own feelings and the suffering and feelings of uncertainty of family members. Dependency of help from family members added to the difficulties of coping with the situation and added further burden to their already difficult situation. Awareness of life and death suddenly being apparent became a turning point in the new situation. Dying is more than a set of medical problems to be solved; dying is a deep personal experience, and ensuring comfort is essential. Despite the future being viewed from an uncertain perspective, the participants were able to enjoy, and to keep illness in the background rather than in the foreground of life. The findings in this thesis might have important implication for the care of elderly with cancer. Health-care professionals need to focus on the patient's perspective of getting cancer in old age, and thereby identify the specific meaning the turning point has for the individual, and to understand the particular approach he or she has to managing the awareness of being old.

In caring for elderly with cancer based on this thesis, it is recommended to set up appropriate intervention strategies aiming to identify a person's resources. Such intervention may pay attention to the complexity of the trajectory associated with cancer in old age, and strive to focus on patient's ability to handle the situation and strengthen the feeling that there is a way out of difficulties for the elderly with cancer. This may perhaps facilitate the transition to living with cancer to be less burdensome. Health care professionals need to empower the voice of elderly with cancer by listening to their experiences and encourage them to a new perspective on their life newly diagnosed with cancer.

FURTHER RESEARCH

The findings from this thesis bring up additional research questions about QoL in elderly newly diagnosed with cancer and the lived experience of getting cancer in old age.

- The study found that QoL did not change significantly over the first six months for the entire sample. Nevertheless, a period of six months perhaps is too short a period to verify important changes in QoL. Investigation of QoL covering a longer period may be important, and more studies are needed to verify which QoL instrument is the most suitable for this specific patient group. Based on the results, further research with focus on what factors may predict improvement in QoL is also recommended.
- Those participants who were non-participants after three and six months were the most vulnerable at time of diagnosis, and suffered from a number of complaints. All of them died within the first six months. Further research to enhance the palliative care as regards symptom control and QoL is required.
- More research is needed to investigate fatigue in the everyday life of elderly with cancer. The focus needs to be on the characteristics of fatigue, the impact in everyday life, and how elderly manage the limitations followed by fatigue. Additional, it is essential to set up a research plan integrating a suitable interventions study to clarify what activities are important to possible obtain control over fatigue.
- The findings show that elderly with cancer found it difficult not being able to manage daily living independently any longer. Especially being dependent on adult children and receiving help from them was problematic. Further research about roles and reactions to dependency in family members is necessitated. Further research on the experience of the adult children being a next-of-kin to an elder parent with cancer is recommended from this study, and in addition, to investigate what it is like to provide help to an elderly person with cancer. Limited knowledge about grandchildren is available within the field of cancer care, and future research should explore matters regarding grandchildren as younger caregivers and how they experience the care-giving situation.
- The relation between QoL and hope in patients with cancer needs further to be investigated, since it is still uncovered despite their close relation. More research is needed to develop and further psychometrically test the Nowotny's Hope Scale to calibrate the instrument for use among elderly people.

POPULÆRVIDENSKABELIG SAMMENFATNING

Summary in Danish

‘Ældre mennesker der lever med kræft. Livskvalitet og livserfaring’

Denne afhandling handler om livskvalitet hos ældre mennesker med kræft. Risikoen for at få kræft stiger med alderen, og til trods for at de fleste mennesker, der får kræft er ældre, har forskning i hvordan ældre lever med en kræftsygdom været yderst begrænset. Viden om hvordan ældre mennesker oplever det at få en kræftdiagnose og hvordan de lever med sygdommen er en forudsætning for at kunne yde optimal pleje.

Det overordnede formål med undersøgelsen er at undersøge livskvalitet hos ældre nydiagnosticerede kræftpatienter fra diagnosetidspunktet og op til seks måneder efter. Formålet er yderligere at undersøge livskvalitet over tid i forhold til faktorer som kræfttype, alder, social-økonomiske forhold, mulighed for at udføre daglige hverdagsdaglige aktiviteter uden hjælp fra andre, kontakt med sundhedsvæsenet, socialt netværk og støtte fra netværket, samt håb. Endvidere er formålet at identificere de personer, der udviklede forringet livskvalitet i løbet af de første seks måneder. Formålet er også at undersøge ældres erfaringer med det at få kræft i en sen alder. Undersøgelsen blev tilrettelagt så flere forskellige metoder kunne belyse samme problemstilling fra flere forskellige vinkler. Afhandlingen omfatter i alt fire delarbejder; tre kvantitative (delarbejde I-III), som var designet som en opfølgingsundersøgelse og et kvalitativ (delarbejde IV).

Deltagere i undersøgelsen var i alt 101 ældre personer nydiagnosticeret med kræft. Deltagerne var fra 65 år og opefter (75 kvinder og 26 mænd, gennemsnitsalder 74,74 år), og ligeligt fordelt mellem bryst-, lunge, tarm- og underlivskræft. Forandringer i livskvaliteten blev målt over tid, det vil sige fra omkring diagnosetidspunktet, så tre måneder efter og endelig efter seks måneder. Efter tre måneder var der 66 kvinder og 19 mænd (i alt 85) tilbage og efter seks måneder 57 kvinder og 18 mænd (i alt 75) tilbage. Det vil sige, at der var et bortfald på omkring 25 % over de første seks måneder, fordi deltagerne enten døde eller var for svage til fortsat at deltage i undersøgelsen. Det var primært dem med lungekræft, der døde. Alle deltagerne var blevet henvist til et ambulatorium på en kræftafdeling (onkologisk afdeling) med henblik på en specialistvurdering. En stor del af deltagerne havde også kontakt til andre afdelinger på andre sygehuse, så som medicinske eller kirurgiske afdelinger, eller til primær sektor (praktiserende læge, hjemmehjælp og/eller hjemmesygeplejerske). Kriterierne for at kunne deltage var at deltagerne skulle kunne tale og forstå dansk, ikke var demente eller lignende, skulle modtage en eller anden form for behandling i onkologisk regi og var informeret om deres kræftdiagnose. Kriterierne for ikke at kunne deltage var demens eller udbredt svaghed. Andre sygdomme var ingen hindring for at deltage i undersøgelsen. Delarbejde I-III var en spørgeskemaundersøgelse, og data blev indsamlet gennem såkaldte personlige strukturerede interviews. Det betød, at forskeren interviewede deltagerne ud fra de spørgsmål der indgik i spørgeskemaet. Alle deltagerne blev interviewet enten i hjemmet, på ambulatoriet eller via telefon. Spørgeskemaet bestod af spørgsmål fra internationale anerkendte standardiserede undersøgelsesmetoder, der handlede om livskvalitet, socialt netværk og støtte, uafhængighed i at udføre dagligdags aktiviteter samt håb. Endvidere

blev deltagerne spurgt om deres sociale, ægteskabelige og uddannelsesmæssige status. Også spørgsmål om børn og børnebørn, samt om deres kontakt med sundhedsvæsenet blev de spurgt om.

Den kvalitative undersøgelse (delarbejde IV) var en fænomenologisk undersøgelse. Fænomenologiens hovedidé er at få indsigt i menneskers erfaringer med et bestemt fænomen. I denne undersøgelse indgik 16 personer (alle fra opfølgingsundersøgelsen, 12 kvinder og 4 mænd, i alderen fra 68 til 83 år). I denne undersøgelse var det fænomenet: 'livserfaring ved det at få kræft som ældre', der blev undersøgt. Måden at opnå denne indsigt på var et åbent dybdegående interview. De ældre fik stillet et enkelt spørgsmål: 'Jeg er interesseret i at vide, hvordan det er at leve med en kræftsygdom når man er ældre. Vær venlig at fortælle mig om din erfaring'. De ældre fik mulighed for at fortælle om deres erfaringer og hvilke områder der havde betydning for dem. Interviewene forgik alle i de ældres hjem og blev optaget på en båndoptager. Interviewene varede mellem 60-90 minutter, med undtagelse af et som varede i 15 minutter på grund af svagelighed hos den ældre. Interviewene blev senere renskrevet og analysen bestod i at identificere essenser i fænomenet med udgangspunktet i teksten.

Delarbejde I

Alle deltagere blev inddelt i fire forskellige aldersgrupper (65-69, 70-74, 75-79, 80 og ældre) og formålet var at undersøge hvorvidt alderen hos ældre havde betydning for livskvalitet og de øvrige faktorer (uafhængighed i dagligdagsaktiviteter, socialt netværk, støtte, og håb). Analysen viste, at der ikke var nogen særlig forskel på livskvalitet i de fire aldersgrupper – de lå alle inden for samme livskvalitetsniveau. Derimod viste det sig, at de ældste (80 år og ældre) overvejende boede for sig selv. De havde et mindre socialt netværk (rent kvantitativt), og havde mere brug for hjemmehjælp end de yngre aldersgrupper. I forhold til hele gruppen var træthed og åndedrætsbesvær de mest fremtrædende symptomer. De faktorer, der havde betydning for lav livskvalitet på diagnosetidspunktet var: 'ikke at have andre indtægter end folkepension', 'at have et lavt niveau af håb', 'at have kræft?', og 'at få information om at sygdommen ikke var helbredt'. 'Afhængighed af hjælp i daglige aktiviteter' påvirkede ligeledes livskvaliteten negativt. Særligt det at 'have behov for hjælp af sine voksne børn' i daglige aktiviteter påvirkede livskvaliteten negativt.

Resultaterne fra denne undersøgelse viser, at den ældre kræftpatients situation ikke nødvendigvis bør forstås som følge af kronologisk alder, altså jo højere alder jo dårligere. Derimod må man snarere opfatte den ældres situation som en individuel proces med særlige individuelle karakteristika af hændelser og situationer. Sundhedspersonale kan på baggrund af denne undersøgelse koncentrere plejen i særdeleshed mod dem, der er i særlig risiko for at udvikle lav livskvalitet: det gælder patienter, der er afhængige af hjælp fra andre, patienter der har begrænsede økonomiske muligheder, der har lavt niveau af håb og som lever med en kræftsygdom, der ikke kan helbredes.

Delarbejde II

De interviewede personer i denne undersøgelse – tre måneder efter – var fra samme gruppe som i delarbejde 1, dog udgik 16 deltagere af undersøgelsen på grund af svaghed eller død. Det vil sige i alt 85 deltagere var tilbage. Træthed var det symptom, der oftest blev rapporteret. Der blev ikke identificeret nogen signifikant forskel mellem livskvaliteten på diagnosetidspunktet og tre måneder efter; livskvaliteten blev hverken bedre eller ringere

for den samlede gruppe. Men nogle patienter med lav livskvalitets-score blev identificeret. Disse patienter var karakteriseret ved at være afhængige af hjælp i daglige aktiviteter, have reducerede økonomiske muligheder på grund af kræftsygdommen samt signifikant lavere niveau af håb tre måneder efter diagnosetidspunktet.

Resultaterne fra dette delarbejde viser, at sundhedspersonale bør være opmærksom på dem, der er afhængige af hjælp i almene daglige aktiviteter og dem, der opfatter at deres økonomiske situation er blevet dårlig, og som bliver dårligere på grund af kræft sygdommen. Patienter med lavt niveau af håb, har brug for hjælp til at få nye strategier og til at styrke håbet for at opnå en bedre livskvalitet.

Delarbejde III

Formålet med dette delarbejde var at undersøge mulige forandringer i livskvaliteten fra diagnosetidspunktet, tre måneder og seks måneder efter. Deltagerne var reduceret til 75 i alt; 26 udgik på grund af død, generel svaghed eller hjernemetastaser. For hele gruppen var livskvaliteten uforandret over de første seks måneder, hvorimod deres følelsesmæssige formåen blev forbedret, og oplevelsen af kvalme og opkastninger var reduceret. De faktorer, der på diagnosetidspunktet kan forudsige lav livskvalitet efter seks måneder blev undersøgt. Lavt niveau af håb var én af de faktorer, der kunne forudsige lav livskvalitet seks måneder efter. Oplevelsen af at have brug for mere hjælp og at have kontakt med hjemmesygeplejersken på diagnosetidspunktet, kunne ligeledes forudsige udvikling af lav livskvalitet inden for de første seks måneder. Det sociale netværk blev oplevet som uforandret i størrelse ligeså var oplevelsen af støtte fra netværket uforandret. Derimod steg behovet for støtte fra både voksne børn og børnebørn betydeligt over denne første periode. Deltagerne blev inddelt i to grupper: dem der havde uforandret livskvalitet (cirka 70 %) og dem med forringet livskvalitet (cirka 30 %). Størstedelen af deltagerne, altså dem der havde uforandret livskvalitet viste, at de var i stand til at tilpasse sig den nye situation som en kræftdiagnose indebærer. Derimod, dem der havde forringet livskvalitet fremstod som en sårbar gruppe, både ved at have brug for hjælp fra sundhedsvæsenet (formel hjælp) og fra familien (uformel hjælp), og hvad angår eksistentielle forhold.

Resultaterne fra denne undersøgelse viste, at det at få kræft som ældre medfører vanskeligheder for de mest sårbare med hensyn til at tilpasse sig de eksistentielle forandringer, hvorimod det at tilpasse sig til forandringer i forhold til sygdommen og symptomer ikke har afgørende betydning. Det ultimative mål for pleje af ældre mennesker med kræft, må være at styrke den enkeltes muligheder for at identificere egne ressourcer i den nye og ændrede situation. Børnebørns kontakt med kræftsyge bedsteforældre må indgå i sundhedspersonalets opfattelse af det sociale netværk.

Delarbejde IV

Formålet med denne undersøgelse var at belyse den levede erfaring hos ældre mennesker der får kræft. Resultatet mandede ud i en hovedessens 'Sygdommen - et vendepunkt der markerer alderdommen'. Dette resultat bestod endvidere af af tre essenser: 'Sygdommen indebærer at miste kontrol', 'Forstyrrelse i familiebalancen' og 'Liv og død bliver pludselig åbenbar'.

Sygdommen indebærer at miste kontrol hvilket betød at den ældre oplevede sig selv nu som at være blevet ældre i en sygdomskontekst. Det var anderledes end man havde

forventet. Det betød også at man blev afhængig af omsorg fra sundhedsvæsenet, hvilket i nogen udstrækning blev oplevet som at have mistet kontrollen og at have fået en ny identitet - som 'kun patient', hvilket var negativt. At miste kontrol betød, at hverdagen var præget af begrænsninger relateret til kropslige funktioner. Ekstrem træthed var et eksempel på at kroppen blev begrænset, men også et tegn på det at blive ældre. **Forstyrrelse i familiebalancen** indebar, at den ældre blev påvirket af, hvordan de nærmeste pårørende reagerede på sygdommen. De nære pårørendes oplevelse af lidelse og følelse af usikkerhed var belastende for den ældre at håndtere. Især børnebørnene blev fremhævet som betydningsfulde pårørende, som nogle den ældre på en særlig måde forsøgte at tage hensyn til. En konsekvens af sygdommen og det at blive ældre, betød problemer med at klare sig selv i det daglige. Det indebar, at den ældre var afhængige af at modtage hjælp fra andre, i særdeleshed fra voksne børn og børnebørn. Det blev oplevet som vanskeligt at tage imod hjælp fordi deltagerne frygtede at være til byrde for deres allernærmeste. **Liv og død blev pludselig åbenbar** og det indebar at livets uundgåelige realitet blev tydelig. Kræftdiagnosen aktiverede tanker om livet og døden, hvilket kunne være smertefuldt. Deltagerne beskrev, hvordan de forestillede sig de gerne ville dø. Døden var ikke noget man ønskede, men trods alt ikke så skræmmende, fordi det var forventeligt. Det betød også, at de på trods af sygdommen og på trods af tankerne om døden, kunne håbe og fortsat nyde livet. Håbet og viljen til fortsat at leve havde overtaget.

Undersøgelsen bidrager med indsigt i de erfaringer ældre kan berette om efter at have fået kræft. Det er betydningsfuldt, at lytte til patienters oplevelser med en sygdom som kræft, og hvordan de håndterer det at leve i en forandret situation. Sygdommen blev som et vendepunkt og markerede ikke kun sygdommen, men også alderdommen. Sundhedspersonale kan ved at lytte til patienters oplevelser med en sygdom få vigtig indsigt i hvad der har betydning for den enkelte patient, og derved fokusere på de muligheder den enkelte patient har og er i stand til at mobilisere.

Konklusion

Resultaterne fra disse fire delarbejder viser, at det er nødvendigt at betragte ældre mennesker med kræft som en heterogen gruppe og ikke som gruppe, der nødvendigvis er svag på grund af alder. Det at få kræft fremstod som et vendepunkt i livet hos den ældre, og størstedelen af de ældre var i stand til at mobilisere ressourcer så de kunne få noget positivt ud af livet med en kræftdiagnose. Det er muligt allerede på diagnosetidspunktet at identificere de ældre med kræft der er særlig udsatte for at udvikle lav livskvalitet; dem med lavt håb, dem der var afhængige af hjælp både fra sundhedsvæsenet (formel hjælp) og fra familien (ufornet hjælp). Sundhedspersonale vil kunne modvirke yderligere forringelse i livskvaliteten ved at tilrettelægge plejen ud fra de forhold som har betydning for patienten. Undersøgelsen understreger, at det er betydningsfuldt at lytte til de ældres erfaringer og hvad der har betydning for dem. Det er værd at fremhæve, at den kvantitative del og den kvalitative del af undersøgelsen bekræftede hinandens resultater.

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