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# Consequences for family members of being informal caregivers to a person with advanced cancer

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*To Daniella and Fredrika*



## Abstract

**Aim:** The overall aim is to generate knowledge about consequences of informal caregiving for the family members of patients diagnosed with advanced cancer, over a one-year period, including the family members' health, health-related quality of life, health care utilization, and associated costs. Furthermore, the family members' management of their stressful daily life and the meanings of social support networks in the early stage will be explored in order to get deeper understanding. **Method:** The thesis is based on two quantitative prospective studies (I–II) and two qualitative cross-sectional studies (III–IV). Studies I–II involved data from the same study group of 36 family members to relative with cancer. Use was made of questionnaires about sociodemographic characteristics, informal caregiving, leisure activities and absence from work (Study I), also of the Short Form 36 Health Survey (SF–36) and EuroQol (EQ–5D) (Study II), during a 1-year period starting 3 months after diagnosis. Study I also included a telephone interview and a review of medical records. Twenty family members were interviewed in Study III, 17 in Study IV; and the interviews were subjected to latent content analysis. **Results:** The findings indicate that family members' informal caregiving influence the risk of morbidity with increased health care utilization and lower health-related quality of life the year following the diagnosis. The number of hours spent giving the patients was highest in respect of emotional support. If professional caregivers as home help care assistants had provided the support, it would be equivalent to a cost of 327,000 SEK per 15 months. The medical records indicated increased morbidity with increased health service use (physician consultations), more psychiatric disorders and more musculoskeletal diseases during the follow-up period (Study I). No statistically significant differences in health-related quality of life (HRQOL) were found within the study group over the 1-year follow-up in either physical or mental dimensions. However, the family members did have mental HRQOL scores significantly lower than the norm-based ones as measured throughout the year by SF–36. In addition, results showed that older age and being a partner had a negative influence on HRQOL (Study II). Management employed by family members during the early stage after patient diagnosis was expressed by the theme *Striving to be prepared for the painful*, based on emotion-focused strategies except the problem-focused strategy to 'Making things easier in everyday life' both for the sick person and for themselves (Study III). The meaning of the social support network was expressed by the theme *Confirmation through togetherness*, covering emotional and, to a lesser extent, instrumental support. Confirmation through togetherness derived principally from information, understanding, encouragement, involvement and spiritual community. Need of support, Desire for a deeper relationship with relatives and Network to turn to were identified as antecedents to social support. Social support involves reciprocal exchange of verbal and non-verbal information

(Study IV). **Conclusions:** The results of this thesis provide knowledge of family members' risk of morbidity, which motivates developing guidelines for preventing both physical and mental morbidity. Developing valid measurement of the meaning of social support network for the individual patient could encourage nurses and other health-care professionals to focus on family members' personal networks as a way to strengthen their mental health.

# Original Studies

This thesis is based on the following studies, which are referred to by Roman numerals in the text:

## Study I

Catarina Sjölander, Bo Rolander, Johannes Järhult, Jan Mårtensson, Per Carlsson, Gerd Ahlström. *Health consequences and costs of informal caregiving among family members of patients with advanced cancer: a prospective follow-up study*. Manuscript submitted

## Study II

Catarina Sjölander, Bo Rolander, Johannes Järhult, Jan Mårtensson, Gerd Ahlström. *Health-related quality of life in family members of patients with an advanced cancer diagnosis: A one-year prospective study*. Health and Quality of Life Outcomes 2012, 10:89. <http://www.hqlo.com/content/10/1/89>

## Study III

Catarina Sjölander, Berith Hedberg, Gerd Ahlström  
*Striving to be prepared for the painful: Management strategies following a family member's diagnosis of advanced cancer* BMC Nursing 2011 Oct 4;10:18.  
<http://www.biomedcentral.com/1472-6955/10/18>

## Study IV

Catarina Sjölander, Gerd Ahlström  
*The meaning and validation of social support networks for close family members of persons with advanced cancer*. BMC Nursing 2012, 11:17.  
<http://www.biomedcentral.com/1472-6955/11/17>





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## Abbreviations and Definition

ICD-10-SE	International Statistical Classification of Diseases and Related Health Problems of the World Health Organisation In Swedish
EQ-5D	EuroQol-5D questionnaire
EQ-5D Index	Index value attached to an EQ-5D state
EQ-5D VAS	Standard vertical 20 cm visual analogue scale
HRQOL	Health-related quality of life
SE	Standard error of the mean
SEK	Swedish krona
SF-36	The Short Form-36 Health Survey
SD	Standard deviation
WHO	World Health Organisation

Advanced cancer	Based on a clinical perspective and refers to the current severe forms of cancer with high mortality rates
Family member	Includes more than just biological relatives or people related by marriage, referring instead to people identified by the patients as playing a key role in their lives [1]
Informal caregivers	Persons providing informal caregiving [2, 3], provided by non-professional lay persons [4]
Social support networks	Consist primarily of family and friends, and not health care professionals [4]

# Introduction

In my clinical and professional work in cancer care I have noticed that staff tend to assume that family members should be there as a resource for the cancer patient. Prior to the discharge from hospital the patient is usually asked whether there are family members who can provide support and care at home. Both health-care and municipal staffs often assume that family members, regardless of their own life situation, are able and willing to become informal caregivers. If the patient does not have a family member ready to take on the role of caregiving, help will be offered by the municipality; but if there is a family member available, this person is expected to take on the role. For the family member this decision can be a further burden, to be added to the shock of the loved-one's having received a cancer diagnosis and to the consequent changes in their shared life. The burden also may have a deleterious effect on the family member's health-related quality of life leading to an increase in his/her own need of health care. The family members' consequences of their informal caregiving in terms of health, health-related quality of life, cost of health care, management strategies and social networks constitute issues which are important to explore, and this is what motivated the undertaking of the present thesis. The family members in this research are relatives to a person who have recently been diagnosed with a life-threatening cancer of the lung or upper gastrointestinal tract.

# Background

Cancer requires substantial resources in medical treatment and care, even when patients are treated at home and there are family members who are expected to take on major responsibility. Medical treatment and medico-technical assistance in the patient's home has become more common [5]. This change in Swedish health care means that family members have to take responsibility for the care of people with cancer, providing informal caregiving and support which complement the medical treatment [6].

## Prevalence and mortality of cancer disease

The number of cancer cases in Sweden has steadily increased over the past 20 years and 55,342 persons with malignant diseases were reported to the Swedish Cancer Registry in 2010 [5]. One explanation of the increased number of cancer diagnoses may be found in the ageing population and the improvement of diagnostic procedures, another in the introduction of different screening programmes [5, 7]. Cancer has become a more chronic or prolonged disease with unknown sequence instead of a fatal diagnosis [7]. However, sixty per cent of all persons diagnosed with cancer were 65 or older in 2007 [8, 9] and about a quarter of Sweden's population will be older than 65 in 2030 [5].

Of the 55,342 persons diagnosed as having malignant disease in 2010, there were 3,697 with cancer of the lung (6.7%), 966 with cancer of the pancreas (1.7%), 839 with cancer of the stomach (1.5%), 833 with cancer of the liver and bile ducts (1.5%) and 388 with cancer of the oesophageal (0.7%). Persons diagnosed with these cancers in Sweden in 2010 were predominantly above the age of 60 [5]. In the County of Jönköping the corresponding number of cancers was 190 (91 in the lung, 99 in the upper gastrointestinal tract) [5].

Carcinomas of the lung and upper gastrointestinal tract still have a very poor prognosis and a majority of the patients die within a short time. Lung cancer in fact is the malignancy leading to most cancer deaths globally [9, 10] and, together with cancer of the pancreas, stomach, liver, bile ducts and oesophageal, it has a five-year survival of only 3.8–23.6 per cent [9]. In Swedish women, lung cancer nowadays is a more common cause of death than breast cancer. About 85 per cent of all patients with lung cancer in Sweden die of their illness, and a large proportion of these patients receive palliative care [11].

When the term “advanced cancer” is used in this thesis, it refers to the clinical perspective of these malignancies with high mortality rates. However, the thesis does not investigate the consequences of these types of cancer for the patient but restricts itself to the consequences for those family members who provide the patients with informal caregiving.

## Palliative care

Palliative care is described by the WHO as directed towards improving the quality of life of patients and their families facing the problems associated with life-threatening illness. It is important that there shall be prevention and relief of suffering by means of early identification, assessment and treatment of pain and physical, psychosocial and spiritual problems [12, 13]. The WHO definition of palliative care is based on the principle of human dignity, and the most important areas to consider in clinical practice are teamwork, communication and relationship, as also support for families. The latter area involves offering participation in the care and offering support during the patient's illness and after the death. The WHO was attention to the need of offering a support system to help the family cope during the patient's illness and their own bereavement [8, 12, 14]. Palliative care had previously focused on cancer, but now also includes patients with progressive, incurable illness or injury [7, 13]. Palliative terminal care is provided as general and specialist palliative care in final phase of the person's life. It can be difficult to determine *when* a person with cancer enters this phase and when the care should shift from being life-prolonging to being soothing. Some persons have a severe prognosis and so the care becomes palliative soon after diagnosis, which is commonly the case when the cancer is spreading [8, 13]. How long this period lasts differs from person to person, but it may be days, weeks or months.

Palliative care has been described as embodying a philosophy of care that focuses on health content regardless of how care is organized [8, 13, 14]. The Swedish National Board of Health and Welfare has decreed that palliative care shall be available to all, regardless of age or diagnosis. Palliative care involves a specific area of knowledge and should be part of all care, regardless of where and by whom the care is offered. Palliative care includes several disciplines. The National Board of Health and Welfare defines one of these disciplines, palliative medicine, in terms of the provision — for patients with active, progressive and advanced disease — of medical care focusing on patient quality of life: physical, mental, social and spiritual. The specific focus on the human being is directed towards actively promoting the experience of health and well-being in the context of terminal illness and at the end of life from a multidimensional

perspective [8, 15]. The recently developed national programme for palliative care in Sweden has been created in collaboration with the Regional Cancer Centres [8]. The National Board of Health and Welfare's health-care programmes are available for breast, colorectal and prostate cancer care, as well as lung cancer care. Work is in progress for the establishment of seven national health-care programmes concerning gastrointestinal cancer for instance liver and bile ducts cancer, oesophageal and stomach cancer, and pancreatic cancer [8, 16, 17]. Palliative care was not in focus in this thesis from the start. During the follow-up, however very many patients were found to have a very severe prognosis (and indeed very many of them died during the study period). This meant that the question of palliative care took on greater importance in this study.

## Informal caregiving

The National Board of Health and Welfare [18] was commissioned by the Government to draw up a report on informal caregivers who regularly provide caregiving for close relatives. There is no available register of informal caregivers in Sweden. The report showed that about 1.3 million members of the population in Sweden regularly provide informal care, of whom about 900,000 are of working age. Informal caregiving is most usual in the 45–64 age group (25%), followed by the 65–80 group (19%) [18]. The person 65 or older is usually providing care for his or her partner.

Different terms as informal caregivers, family caregivers and carers are used in the literature when the person/persons who are closely related to someone who suffers from illness or disease, or who is in need of care. The concept of informal caregiver is in common parlance someone who has undertaken to perform certain health and social care [19]. The term “family” is taken to include more than just biological relatives or people related by marriage, referring instead to people identified by the patients as playing a key role in their lives [1], but in this thesis the term is taken to indicate caregivers, which is to say persons providing informal caregiving [2, 3]. The terms “family members” and “informal caregivers” are used interchangeably. Informal caregiving is mainly non-

professional and provided by lay persons [4]. Informal caregivers are providing psychological support to terminally ill cancer patients and they also need psychological support by themselves [20, 179]. A review of relatives in end-of-life care by Andershed and colleagues [21] showed that being the relative of a person who has a life-threatening disease is experienced as burdensome and as being in an exposed position with increased responsibility [21]. The caregiving can be provided out of love but also out of a sense of responsibility [22]. Family members may decide to provide palliative home care out of a desire to fulfil a promise to the patient that he or she would be cared for at home and also out of a desire to maintain a normal family life [23].

Informal caregiving has commonly been studied in connection with the caregiver's role and needs often in relation to their life situation as a partner. Well-described areas of informal caregiving are those concerning close family of people with cancer in relation to burden [24-29], depression [25, 26, 30-32], distress [33, 34] and health-related quality of life [26, 35, 36]. Caregiving is described as a complex area associated with multiple concurrent stressful events [37]. Symptom burden is a multifaceted clinical and social problem affected both by patient and caregiving characteristics [38].

A systematic review by Bee and colleagues [39] of informal caregivers needs within palliative care has shown that there is a lack of practical guidance and that they receive less practical professional support and information than they needed [39]. Caregivers are mostly alone in providing support for the cancer patient in the patient's home [40]. Plant and colleagues [41], in a study of nurses' experience of providing a supportive intervention for family of patients with lung cancer, show that the family members try to preserve the well-being of the person with cancer through emotional and practical support more for the sick person's life and well-being than concerning themselves. In a study by Persson and colleagues [28] the family members are seen to be struggling to accomplish the transition process in the midst of their changing life distress. Similarly, a review by Ellis [42] of the impact of lung cancer on caregivers indicated that the caregivers were going through a transition process because of the diagnosis and were struggling to overcome problems and distress. The period immediately following the diagnosis is usually characterised by doubts about the future and



an effort to be prepared for negative outcomes [43, 44]. There seems to be a distinct risk of psychological distress for the family members overall [29, 31, 45-47]. Caregivers need to be better helped with special support programmes for the role of informal provider of care, as well as with regard to their health.

## Health and health-related quality of life

Health is defined as a complete state of physical, mental and social well-being, and not merely the absence of disease or infirmity according The National Board of Health and Welfare based on the WHO definition [48, 49]. The concept of health includes professionally assessed measure dimensions as well as self-rated dimensions related to their own ability [49]. Boorse developed in the 1970s, the medical conceptions of health. The biostatic theory defines health as the absence of disease, and disease as being opposed to health. This theory is based on statements on normality [50]. Normality is expressed in statistically calculated values adjusted to the reference value corresponding to the individual's gender and age. In this way, what is healthy or ill determined numerically. Those who fall within the statistical framework therefore considered as healthy. Boorse define disease due to a medically-defined function and illness as the individual experiences of illness, objective respectively subjective health [50].

The concept of health-related quality of life (HRQOL) concerns people's subjective perception of their health, including their experience of social, mental and physical well-being. Self-assessment of HRQOL has the strength that it reflects the person's perceived health strong correlation with disease [51]. It is used as a general tool for measuring health status and has been particularly useful in the case of disease-related groups of patients.

Some studies have reported the mental and physical health of family caregivers to person with cancer as being comparable to that of the general population [52], others have reported caregivers' HRQOL as being negatively affected by the situation [27, 53, 54]. The physical health dimension has been less studied but problems have been reported with regard to such areas as pain, sleep disturbances, fatigue, loss of appetite and weight loss [55, 56]. The informal

caregivers are influenced by the cancer diagnosis and the treatment as well as the patient distress [57]. Indeed, significantly more caregivers than patients are anxious [29, 57, 58]. Previous studies have shown a decline in the mental health of family members caring for persons with cancer, with symptoms such as depression and anxiety [26, 30-32, 45, 46]. There is a need of knowledge about the burden and costs of caregiving as well as health care. Few studies have focused on acquiring such knowledge [59, 60], or on the development of appropriate instruments for doing so.

## Cost of informal caregiving and health care

A patient's disease affects the family members. There may be increased costs for the family members, but also a reduced quality of life [61]. The risk of poor health outcomes has to be identified in order to better support the struggling caregivers [37, 62, 63]. The role of caregiver can involve a restriction on activities and leisure-time [145], which can negatively affect the caregivers' mental health [64-66]. Informal caregiving may also have some influence on work attendance and productivity, creating an economic burden for the family [67-69]. Health-service professionals are considered when family cannot provide informal care [4, 70].

Instruments in earlier research have usually been developed for measuring costs in connection with a patient's particular treatment or for a shorter period than one year [69, 71, 72]. Few studies have been concerned with structured questionnaires that permit the estimation of financial costs for caregivers during the first year after the cancer diagnosis [73], and such costs are rarely included in health-economic analyses. Despite all the recommendations that the cost of informal caregiving should be included to fulfil a societal perspective, there is still a debate as to how this cost should be calculated [74]. In addition to the cost of informal caregiving, the closely related quality of life is affected, which is not usually included in the health-economic analyses. If an analysis is to be consistent in the use of a societal perspective, all the consequences for informal caregivers need to be included [61].

Van den Berg and colleagues point to a problem when it comes to putting a value on informal caregiving: there are no market prices and the care is usually unpaid [75]. There are two methods commonly used to measure the amount of time spent on informal caregiving. One, called the diary method, is that informal caregivers daily report how many hours of informal caregiving they provide. The other, called the recall method, is that the informal caregivers estimate how much care they have provided for a certain period. This method is often used in questionnaires or interviews [61, 75]. To estimate the cost of informal care, the number of hours expended on this caregiving is valued. The opportunity cost-method calculates the informal caregivers time as the persons best alternative use of that time. If the proxy good method is used, the calculation is of what it would cost to have a health-care professional provide the same care [61].

There is no single way to best value the cost of caregivers' time [76] or a single source for comprehensive health-care utilization and cost data. Administrative data sources are usually considered to be the most accurate, but their use is limited because some components of utilization are not systematically captured in decentralized health care systems [77], including informal caregiving by family members. Caregivers have numerous health-related problems, such as sleep disturbances and fatigue, which worsen as the patient's physical function and symptom burden increase [38]. Knowledge of family members' ill-health, in the clinical sense, will provide a better understanding of their health-related problems in relation to health-care use costs. Where the cancer diagnosis negatively affects the family member's mental health, particular strategies for better managing the situation can be of considerable value.

## Coping

There is a need to help caregivers by providing them with better information about their new life situation and about how to cope with the burden of illness [78-80]. The process of managing living with cancer in the family can change over time in accordance with changing circumstances. The time when the threat appears can affect their psychological well-being. Cognitive theory focuses on what the person is thinking, doing or feeling in a specific situation [81]. It is

possible to distinguish between problem-focused and emotion-focused coping. Problem-focused coping implies grappling with the problem by acting or seeking information. Emotion-focused coping implies regulating one's distress by avoiding feelings or situations reminding one of the source of this distress, and it can also be a question of seeking support [81-83]. Persons providing informal caregiving for cancer patients have a tendency to use both problem-focused and emotion-focused coping strategies in respect of the most traumatic events [84, 85]. Problem-focused coping strategies have been of great help to caregivers in the case of patients with cancer [86], though in fact there has been little research on family members' coping strategies [87]. Gaugler and colleagues [88] found that worrying and expecting the worst, have negative psychological outcomes on the mental health of persons providing informal caregiving for cancer patients [88]. The person's managing distress partially depends on the support he or she receives from the family and the social network, and social support is regarded as a resource for management stress [82, 89, 90].

## Social network and support

One approach to defining social support is to make a distinction between structural and functional support [91]. Structural support implies a network of interpersonal relationships involving relatives, friends, co-workers through which the person is attached to a community. Functional support is described in terms of the provision of information, tangible support and emotional support [4, 91-93]. A support network can be a resource for family members in a time of crisis [94-96]. The achievement of better health includes the interaction of people who give each other emotional support, informative material and practical support. The aim are to giving people the possibility of control over the factors that influence health and decreasing the negative factors that cause social strain [97]. Social support can be described as a resource that other people constitute for a specific person. It involves the mutual exchange of information that is characterised by advocacy [89], and described with affect, affirmation and aid [98]. It can also be described in terms of being in contact with people one has trust in, people who care and who value one as a person [99].

Earlier studies have shown that less social support can involve an even greater risk of psychological distress for the family than for the patient [100, 101]. Not having access to support or social networks causes an increased risk of depression for close family of cancer patients [33, 102]. Daly and colleagues [103] showed that younger caregivers have reported less family support than older ones. Though family members such as siblings and adult children have shown lower levels of psychological distress than spouses, they are nevertheless at risk for increased depression [104].

## Rationale for this thesis

During recent years there has been increased demand that health-care professionals should provide support for the caregivers as well as the patient. The health of caregivers needs to be protected, and support should be offered at an early stage to reduce their mental and physical stress [105]. Greater knowledge about family members shortly after the diagnosis means greater opportunity to provide the best possible prevention programme for the family from the beginning of the illness trajectory. However, there are only a few municipalities in Sweden which provide direct support for families in order to preventing illness and improving the health of caregivers [106].

Earlier research includes few studies examining the impact on family members' mental and especially physical health [56, 107]. Though research on family caregiving has increased noticeably since 2000, there is still a need of further research on caregivers health [108]. This in spite of the fact that living together with a person with advanced cancer can involve both physical and mental stress in daily life [47, 108, 109, 143, 149]. It is a particular burden for the family member to support the cancer patient throughout the trajectory of the illness and make life easier for him or her. Persons providing informal caregiving for cancer patients strive to handle their difficult situation and strengthen their quality of life, but such efforts have not been scientifically evaluated sufficiently and therefore further research is needed [87, 110]. Provision of high-quality cancer care services should include strategic support that takes into account the family members' own resources. One approach is to study their health over time and

identify the health-care costs involved in informal caregiving. Focusing more on preventive interventions directed towards caregivers will be conducive to improved well-being both for the caregivers and for the patients. The implementation of evidence-based interventions of this type requires a broad research base concerning the consequences of providing informal care in respect of family members' health, health-related quality of life, health-care costs, cost of informal caregiving and own resources in terms of coping and support from those around them. The findings of this thesis can be useful for health-care staff offering psychosocial interventions and also in health-policy decision-making with regard to prevention programmes.

# Aim

The overall aim is to generate knowledge about consequences of informal caregiving for the family members of patients diagnosed with advanced cancer, over a one-year period, including the family members' health, health-related quality of life, health care utilization, and associated costs. Furthermore, the family members' management of their stressful daily life and the meanings of social support networks in the early stage will be explored in order to get deeper understanding. The specific aims of the studies were:

- to investigate the type of social support provided to patients with advanced lung or gastrointestinal cancer, to estimate the consequences of informal caregiving on the family members' health, and to estimate the economic costs of health service use and informal caregiving (Study I)
- to investigate HRQOL in family members of patients with advanced lung or gastrointestinal cancer over a 1-year period (Study II)
- to explore management strategies that family members employ when the patient is in the early stage of treatment for advanced lung or gastrointestinal cancer (Study III)
- to explore the meaning of social support networks for family members of adult persons in the early stage of treatment for advanced lung or gastrointestinal cancer, furthermore to validate the empirical findings of the present study by means of a conceptual model of social support devised by Finfgeld-Connett (Study IV)

The term "family" is taken to include more than just biological relatives or people related by marriage, referring instead to people identified by the patients as playing a key role in their lives [1], but in this thesis the term is taken to indicate caregivers, which is to say persons providing informal caregiving [2, 3].

# Methods

## Study Design I-IV

This thesis has a mixed-methods embedded design [111, 112]. Embedded design is used in quantitative and qualitative approaches in tandem, to embed one in the other in order to provide new or more refined insights for the purpose of achieving a more complete understanding of a problem [113]. The data collection and analysis are combined in a quantitative and qualitative research design. The purpose of the embedded design in this thesis is that different types of question are needed to be answered by different types of data. The application of a quantitative and qualitative design was to address the primary purpose of this thesis. The strength of embedded design are that different methods are addressing different questions and the design fit the team approach, when the authors in the studies can focus their work on questions based on their expertise. This focus on different questions means that the result can be published separately, but still focus on the aim of the thesis [112]. Qualitative methods provide deeper content and thus complement quantitative methods where the pattern of statistical results can be generalized across populations or settings [114].

This thesis consist of two studies with comparative, prospective quantitative design (Studies I-II) and two studies with inductive qualitative cross-sectional design (III-IV) emanating from the same cohort of family members but including different number of the cohort (Table 1). Study I covered the year prior to the cancer patient's diagnosis and the year after it, whilst Study II covered only the year after the diagnosis. Studies III and IV included qualitative interviews in the early stage following the diagnosis. Study IV also validated the findings with a concept model based on a meta-synthesis. Data collection for the four studies started at the same time, with follow-up studies in order to strengthen the design [114]. An overview of the designs and methods is presented in Table 1.



Table 1. Overview of study designs and methods.

Study	Design	Participants	Data collection	Methods of analysis	Time frame related to patient's diagnosis
I	Prospective Comparative	36 family members of patients with advanced cancer of the lung (n=24) or gastrointestinal tract (n=12)	-Questionnaires: <i>Informal caregiving</i> -Telephone interview: <i>Support from others</i> -Medical records: <i>Health service use, Diagnoses</i> -County council's administrative system: <i>Cost of health service use</i>	Descriptive and analytical statistics  -Chi-square test -Fisher's Exact test  -Cost estimate <i>Cost of informal caregiving, Cost of absence from work</i>	One-year period for all data except diagnosis and health care utilization, which covered two years: one year before and one year after the cancer diagnosis
II	Prospective Comparative	36 family members of patients with advanced cancer of the lung (n=24) or gastrointestinal tract (n=12)	Questionnaires: <i>Health-related quality of life</i> (SF-36 and EQ-5D)	Descriptive and analytical statistics  -Chi-square test -Mann-Whitney U test -Linear Mixed Models with repeated observations -Logistic regression analysis -Spearman	One-year period, 3 months to 15 months after diagnosis
III	Inductive Descriptive Cross-sectional	20 family members of patients with advanced cancer of the lung (n=10) or gastrointestinal tract (n=10)	Qualitative interview: <i>Management strategies</i>	Qualitative latent content analysis	Diagnosis up to 3 months earlier
IV	Inductive Descriptive Cross-sectional	17 family members of patients with advanced cancer of the lung (n=10) or gastrointestinal tract (n=7)	Qualitative interview: <i>Social support networks</i>	Qualitative latent content analysis	Diagnosis up to 3 months earlier

## Sampling procedure and participants

### Sampling procedure (Studies I-IV)

The family members included in Studies I-IV had a sick relative who up to 3 months earlier had been diagnosed as having advanced cancer of the lung or of the upper gastrointestinal tract at one medical and two surgical clinics of two hospitals in the south of Sweden. The catchments area of the clinics was a county council area with a population of 337,000. At the time of the inclusion the patients were receiving, or in preparation for receiving, cancer treatments such as radiation, chemotherapy and surgery. Gastrointestinal cancer in this thesis includes cancer of the pancreas, oesophageal, liver, bile ducts or stomach.

The family members had to be older than 18 years and able to speak Swedish. An inclusion criterion in the case of Studies III and IV was that approximately half of the family members should be close to persons with lung cancer and approximately half close to persons with gastrointestinal cancer, this in order to obtain variations in the data.

The staff at the current clinics was instructed to support inclusion of the participants until the number of included family members in the cohort was at least 60 family members. The number of participating family members achieved after 200 patients received oral and written information about the aim of the study by eleven nurses and two physicians and asked if they were willing to give written information about the study and participation to the family member closest to them. The patients who consented received two letters, one to themselves and one to the chosen family member. The family member that agreed to participate answered by way of a reply form in a postage-paid return envelope and was contacted by telephone by the first author. The information letter to the family member designated 5 measurement occasions and interviews.

### Participants (Studies I-II)

When sixty-four family members had agreed to participate in Studies I and II (Figure1) the inclusion procedure was stopped, but 7 of them changed their minds and withdrew before the study began because the patient was too ill. Of the remaining 57, 21 dropped out during the study period of the same reason or

because the patient died. Thus 36 family members completed all data collection in Studies I and II. Furthermore, 32 family members also accepted their medical records to be reviewed (Study I). A flow chart of patients and family members during Studies I-II is presented in Figure 1.

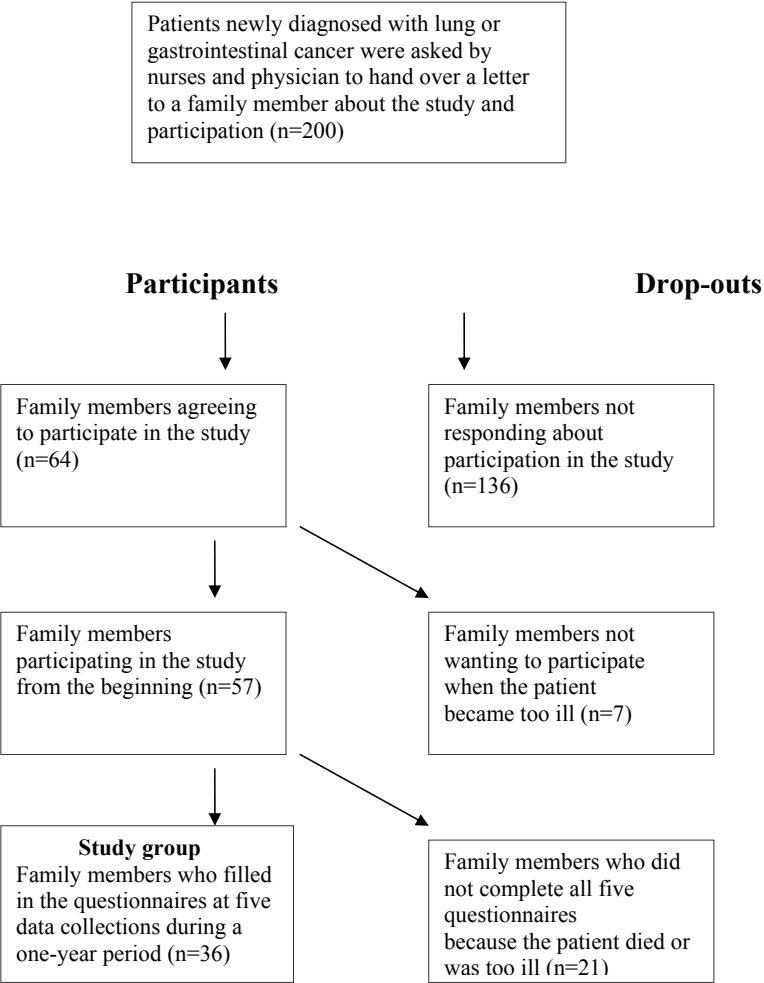


Figure 1. Flow chart of patients and family members during Studies I-II

### Participants Studies (III-IV)

The first consecutive family members to relatives with lung respective gastrointestinal cancer in the study cohort (n=57) were also interviewed in the case of Study III including 20 family members, and in the case of Study IV including 17 family members (Table 2). All family members in these studies who were asked agreed to be interviewed. The two studies were based on the same interview but carried out as two parts with different questions (Table 2).

All participants' (Studies I-IV) characteristics, including age, gender, relationship, education, living situation, work status and education, as also patients' type of cancer, are presented in Table 2.

Table 2. Characteristics of family members in Studies I-IV

<b>Study</b>	<b>I-II n=36</b>	<b>III n=20</b>	<b>IV n=17</b>
<i>Age, years</i>			
Mean	63	60	56
SD	16	15	15
<i>Gender</i>			
Male	10 (28)	4 (20)	4 (24)
Female	26 (72)	16 (80)	13 (76)
<i>Relationship</i>			
Partner	26 (72)	13 (65)	10 (59)
Grown child	8 (22)	5 (25)	5 (29)
Other relative	2 (6)#	2 (10)□	2 (11)□
<i>Living situation</i>			
Sharing household with the patient	26 (72)	13 (65)	10 (59)
Separate household	10 (28)	7 (35)	7 (41)
<i>Work status</i>			
Currently working	14 (39)	13 (65)	11 (65)
Retired	19 (52)	5 (25)	4 (23)
Student	-	1 (5)	1 (6)
On sick leave	3 (9)	1 (5)	1 (6)
<i>Education</i>			
Upper secondary and above	24 (66)	11(55)	10 (59)
Less then upper secondary	12 (33)	9 (45)	7 (41)
<i>Patients' type of cancer</i>			
Lung	24 (66)	10 (50)	10 (59)
Pancreas	8 (22)	6 (30)	5 (29)
Oesophageal	2 (6)	2 (10)	-
Stomach	1 (3)	1 (5)	3 (12)
Liver	1 (3)	1 (5)	-

Note: #I-II Other relative (one ex-partner and one sibling); □III-IV Other relative (one ex-partner and one uncle).

# Data collection

The timing of the data collection is presented in Figure 2. Family members who gave their written consent to participate received an instructive cover letter and questionnaires about given support and health-related quality of life (HRQOL). The first consecutive family members to relatives with lung cancer respective gastrointestinal cancer were interviewed (Study IV and Study III) up to three months after the diagnosis.

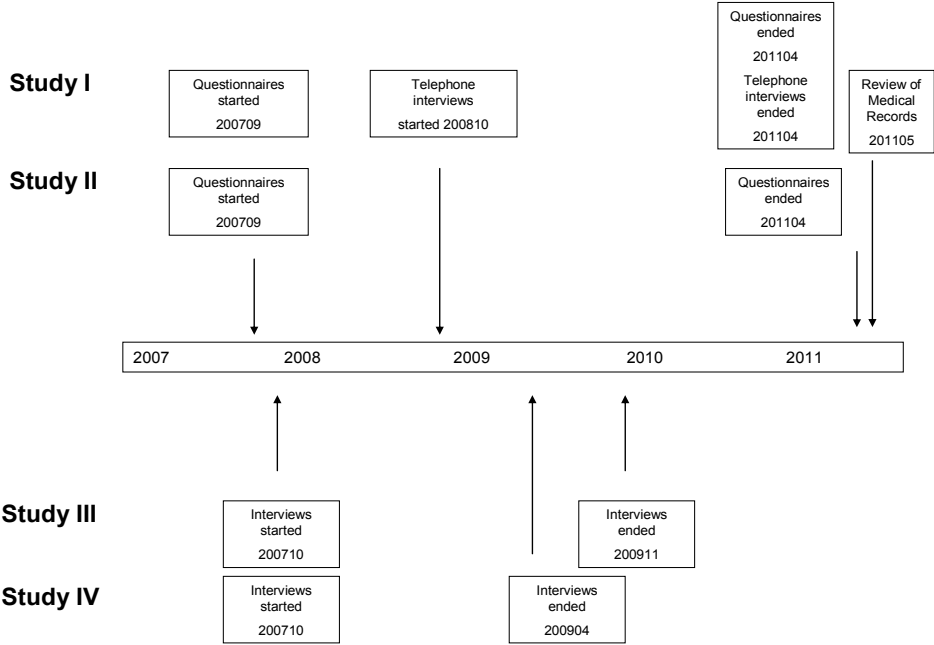


Figure 2. Data collection over time in Studies I-IV

A cover letter was sent every three months additional four times, including the same questionnaires as in the initial assessment. To reduce drop-outs (Studies I-II), family members were phoned a week before every data collection to remind them that the questionnaire was going to be sent to them. If no response was returned a reminder letter was sent again after two weeks.

At the time of the fifth assessment, the author phoned the family members and asked whether they were willing to allow access (n=36) to their medical records. The family members (n=32) who were willing to allow such access sent their identity number and signed consent by post to the first author. Subsequently a senior physician studied these medical records, obtained by way of the identity number. One month after the fifth measurement the data collection was completed with a telephone interview.

## Questionnaires and interviews

Three questionnaires were used in this thesis, a self-reported questionnaire concerned the family member's sociodemographic characteristics, informal caregiving, leisure activities and absence from work (Study I). The other two questionnaires were about HRQOL; the Short Form Health Survey (SF-36), and the EuroQol (EQ-5D) (Study II). These two questionnaires were considered complementary in respect of different variables of similar dimensions.

### Self-reported questionnaire (Study I)

The self-reported questionnaire (Table 5) was constructed by the first author (CS) on the basis of the literature and clinical experiences as social worker. It comprised ten questions, half of them with opportunities for the family member to give comments. The sociodemographic information was collected by means of five questions and concerned relationship to the patient, sex, age and work status. Informal caregiving was measured by means of two questions, leisure activities by two questions and absence from work by one question. The first question asked whether they provided support or not. If they did, they were asked how many hours they had spent providing different types of support in the last week. Then there were questions about the number of hours spent on weekly activities and the number of hours refrained from such activities due to supporting the patient. The final question concerned the number of hours the family members had been absent from work in the last week in order to support the patient.

### Review of medical records (Study I)

Data were collected regarding family members' frequencies of health service use in terms of outpatient and inpatient contacts, including both visits and telephone calls. The identified inpatient contacts consisted of medical examinations and associated X-rays and laboratory tests. The identified outpatient contacts consisted of visiting physicians, nurses, physiotherapists, occupational therapists and counselors, both at district health centres and specialist hospital-based clinics. The frequencies of outpatient surgical procedures were also registered. Main and secondary diagnoses were classified in accordance with the International Statistical Classification of Diseases and Related Health Problems, ICD-10-SE [115].

### SF-36 (Study II)

The widely all over the world used SF-36 measures a broad health status, and comparisons are possible among different populations [116]. The SF-36 Health Survey (SF-36) is a self-assessment instrument for measuring HRQOL. It contains 36 items that by means of an algorithm are transformed into eight scales that measure on the one hand the physical health dimensions in four scales; Physical Functioning (PF), Role Physical (RP), Bodily Pain (BP) and General Health (GH). The other four scales measure the mental health dimensions by Vitality (VT), Social Functioning (SF), Role Emotional (RE) and Mental Health (MH) [117, 118]. The questions in each dimension cover the range from 0 (worst possible health state) to 100 (best possible health state), with higher scores reflecting better HRQOL. The eight scales are also presented into two summary score scales: PCS (Physical Component Summary Score) and MCS (Mental Component Summary Score) in accordance with the standard SF-36 algorithms [117, 119].

### EQ-5D (Study II)

EQ-5D is an often-used instrument that has the advantage of having age- and sex-specific norm scores derived from a representative population from the UK [120-122]. EQ-5D consists of items given different weights on the basis of previous studies [123]. It has been used in studies on informal caregivers [124],



including measuring the time spent on care tasks and financial issues [121, 125, 126]. The EQ-5D is a self-assessment instrument measuring HRQOL by means of index scores and a visual analogue scale (EQ-VAS) [123]. It comprises five items of measuring mobility, self-care, usual activities, pain/discomfort and anxiety/depression. In every dimension a choice can be made among three levels of severity (level 1=no problem, level 2=some/moderate problems, level 3=severe/extreme problems). The items are transformed by means of an algorithm from the EQ-5D manual. A higher score reflects a better state of health. The EQ-VAS has a 20 cm vertical analogue scale formed by drawing a line from the box to the thermometer with the worst imaginable health state today (0) to the best imaginable (100) [121-123].

### Telephone interview (Study I)

An interview guide was created concerning the patient support from the family member and from the social network by the first author (CS). The telephone interviews (Figure 2) were conducted last in the data collection procedure, between autumn 2008 and spring 2011. Three main open-ended questions regarding the family members' views on support were asked: Have you been alone in the support of the patient? Who are the persons who make up the patient's support network? What support has the patient received from their support network? Follow-up questions were asked in order to clarify and enrich the information given: "Can you tell me more about the support you received?" "Can you tell me more about the people in your support network?" The telephone interview lasted 15–30 minutes (average 20), and the answers were written down as the interview proceeded [127].

### Interviews (Studies III-IV)

Study III and Study IV was generated from the same interview but consisted of two parts in the interview guide. The face-to face interview lasted 60–90 minutes (average 75), were tape-recorded and transcribed verbatim. The interviews were conducted at hospitals, or at family members' homes or their places of work according to what the family members' desire. The main opening questions in Study III concerned how the family members handled their everyday lives:

“How does your close relative’s cancer affect your day-to-day life?” “How do you manage the situation?” The follow-up questions were designed to shed more light and add more detail: “What do you think about the situation?” “How do you feel about the situation?” “What do you do about the situation?” “Have you anything more to add about that?”

The main opening questions in Study IV concerned the family members’ views on support in relation to their relative with cancer: “What does the term ‘support’ mean to you?” “Who are the persons who make up your support network?” “What personal support have you received?” The follow-up questions were designed to clarify and enrich the information given: “Can you tell me more about the support you received?” “Can you tell me more about the people in your support network?”

## Analysis

### Statistical analysis (Study I)

The provision of informal caregiving for patients was investigated within the framework of a one-year post-diagnosis period. To estimate the time spent on caregiving in Study I, the number of hours per person was calculated throughout the study period. The number of family members who reported providing support in the questionnaire was multiplied by the average number of hours spent caregiving. This result was multiplied by 12 (i.e. the number of weeks) to get an estimate of the average number of hours for each period M1–M5. The total number of hours spent on providing different types of support in the different periods (covering the 15 months of the study) was divided by 36 (i.e. the number of people). The hours of absence from work and hours refraining from weekly activities to support the patient were estimated in the same manner.

The costs of various support activities and absence from work during the previous week for the family members were estimated by multiplying the hours by the average hourly wage of a nurse’s assistant in the home help service, including holiday and social security contributions [128]. This

calculation is based on the fact that health service for severely ill patients at home could be provided at any time of the day by professionals.

Family members' health service use (inpatient hospital days and outpatient consultations), health service costs based on data from medical records (inpatient hospital days and outpatient consultations) and frequencies of diagnoses were investigated one year pre-diagnosis and one year post-diagnosis with Chi-squared tests. Data on cost were extracted from the current county council's administrative system and costs for each service were calculated in 2011 prices by inpatient hospital days and outpatient consultations. The International Statistical Classification of Diseases and Related Health Problems (ICD-10-SE) [115] was used in the classification of the family members' main and secondary diagnoses. Chi-squared tests were used to compare the sociodemographic characteristics in the sample. Family members' usual weekly activities and refrainment from usual weekly activities were compared by means of Fisher's Exact Tests. The significance level was set at  $\alpha = 0.05$ .

## Statistical analysis (Study II)

Family members' health-related quality of life (HRQOL) was investigated over a one-year period (3–15 months after diagnosis). Changes in family members' HRQOL were analysed by means of Linear Mixed Models with repeated observations and the restricted maximum likelihood (REML) method, with separate comparative analysis of each value, with 1 as baseline (3 months after the patient's diagnosis), from 3 months and 15 months. Mann-Whitney U Test was used by independent samples between age group and between family members' relationship to the patient. Statistical analyses with regard to age, gender, relationship, living situation, work status and education were subjected to a Chi-square test. The drop-out group was compared with the study group and examined using chi-square test. The Spearman Correlation Coefficient was used for comparison of the associations between age and relationship to the patient with cancer (partner or grown-up child). A stepwise logistic regression analysis using the forward Wald method was conducted on all five assessments with the eight scales in the SF-36 as independent variables and age and relationship as

dependent variables. The age variable was dichotomised on equal percentiles into the groups 20–65 and 66–84 years, since the study group was small. The significance limit was  $\alpha = 0.05$ . Statistical differences were tested between norm-based scores for the SF-36 and EQ-5D and the respective mean scores at A1–A5. Because age may be an important factor in HRQOL, it was important to get a comparable age structure in a comparison of scores of the study group and norm-based scores. The significance limit was  $\alpha = 0.05$ .

### Qualitative Analysis (Studies III-IV)

The interviews were subjected to qualitative latent content analysis in both Study III and IV. Both qualitative and quantitative content analysis implies the systematic reduction and transformation of a message into data, such as can be communicated to other persons. Content analysis has come into wide use in studies within health care in recent decades and comprises a family of analytical approaches [129, 130]. Qualitative latent content analysis is based on an inductive process, involving openness to the context of the data, whereby the underlying meaning of the text is interpreted [129-131]. Use of latent content analysis made it possible to listen to the words in the text and provided a better understanding of the family members' perspective.

### Latent content analysis (Study III)

The interviews were read and listened to several times in order to better capture the richness of the overall meaning. The text was thereafter divided into meaning units. These were then condensed to a descriptive level close to the original text and abstracted into codes, representing interpretation of the underlying meaning. The codes were constantly compared and contrasted with the data, whereby sub-themes emerged. From comparing differences and similarities in the content of the sub-themes, which involved referring back to the codes and condensed meaning units, there emerged an overall theme. Each step of the analysis was discussed by the authors; and the refined codes, sub-themes and the theme constituted the findings [131].

## Latent content analysis (Study IV)

The analyse procedure was initiated in the same inductive way as described in Study III to generate meaning units, codes, subthemes and finally a theme. Finally, in order to illustrate the representative of the findings were the number of meaning units per each sub-themes counted in this study (Study IV). Furthermore, in Study IV the theme and sub-themes were compared with the Finfgeld-Connett conceptual model [4] to highlight the similarities and differences in content. This was performed after completion of the inductive analysis, and the intention was to investigate whether the findings of the present study were applicable and in accordance with previous research in nursing. The concept and research on social support remain inconsistent, despite the large amount of empirical research conducted in health care in the last 20 years. The Finfgeld-Connett metasynthesis was based on studies published from 1987 to 2003 [4]. It was organised in accordance with Walker and Avant's model [132, 133], identifying antecedents (preceding occurrence, cause or event), critical attributes of the study in focus and consequences/outcomes. The comparison between the inductive findings of Study IV and the findings of the metasynthesis started with several readings of the definitions in the Finfgeld-Connett model [4] designating the meaning of the antecedents and attributes of social support [133]. The comparison focused on similarities and differences in a validation process of the content in Study IV.

## Ethical considerations

Ethical approval was granted by the Regional Ethical Review Boards in Linköping, Sweden (ref. nr 101-06, 101-06 T102 and 101-06 T 27-08). The family members received written information about the aim of the study and the voluntary nature of participation. They were also informed that they could terminate their participation whenever they wanted and that doing so would not affect them or the patient in their contact with health care [134].

The family members are in an exposed situation as informal caregivers for a person with advanced cancer. This research was considered essential to acquire greater knowledge and a deeper understanding of their situation — and, not

least, to give them better support to in the future. To make things easier for the family members, the interviews were conducted where and when they wanted. Each interview was adapted in accordance with what the family member desired and had the energy for. The family members were informed that they were able to take a break during the interview if needed. My experience of psychosocial work in health care with advanced cancer patients and their families may have affected the outcome. Given the vulnerable nature of the family members' life situation, there was a relationship-building conversation before the interview; and at the end of the interview there was a short period of reflection on what had been discussed — this in order to ensure that the interviewed did not feel ill at ease or felt that there had been intrusion into the personal sphere. Thus the family members had the opportunity to speak freely before and after the interview. If they expressed sorrow, extra time was taken listening to them during the face-to-face or telephone interview. The family members were informed during the interviews and in the telephone contacts that they had access to professional psychosocial support if needed at the clinic where the patient was currently receiving treatment. The family members were appreciated being able to talk about their situation. Some of them saw things in a new light through talking in this way, asking afterwards about what support could be obtained for themselves and the person diagnosed with advanced cancer.

# Results

## Health consequences and costs of informal caregiving among family members of patients with advanced cancer: a prospective follow-up study (Study I)

### Informal caregiving

The family member's fragile psychosocial life-situation and supporting a seriously ill patient was illustrated in the result through the high rate of mortality among the relative with lung and gastrointestinal cancer. More than half of the family members (30 of 57) who initially participated had a relative who died within fifteen months from the diagnosis. Therefore, the estimated average number of hours spent providing the patients with functional support were highest in the case of emotional support: 926 hours during fifteen months after the cancer diagnosis (Figure 3). The next-highest figure was for household work: 444 hours. These results were derived from the study-specific questionnaire on informal caregiving (Figure 3). The cost of the family members' average number of hours spent giving functional support, in terms of salary, during 15 months after the cancer diagnosis was nearly 327,000 SEK (\$46,000). The cost of the emotional support was estimated to 178,000 SEK (\$25,070) and house hold work to 85,000 SEK (\$11,971) (Study I, Table 5).

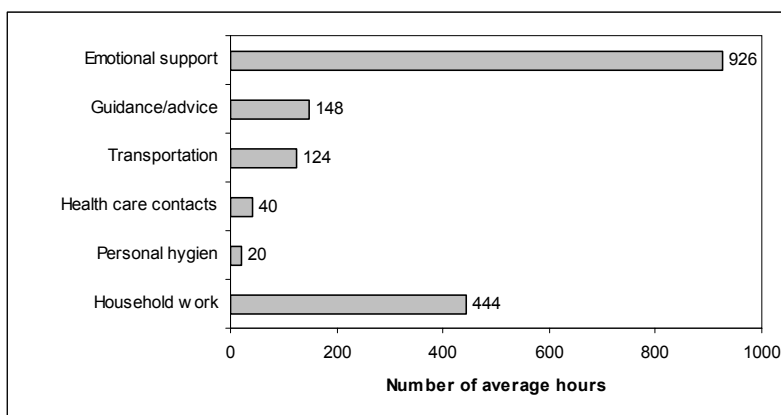


Figure 3. Family members' provision of functional support during 15 months after the patient's cancer diagnosis (n = 36)

### Influence on work and leisure

Absence from work because of informal caregiving provided by family members during the post-diagnosis period was estimated to 121 hours per family member and 4,369 hours for the whole study group. Mostly, the family members did not report refraining from weekly leisure activities (Study I, Table 3). The total cost of absence from work was estimated to SEK 838,848 (\$118,147).

### Influence on health

The family members' diseases were classified in accordance to ICD-10-SE during the year prior to the patient's diagnosis. There was a significant increase in the number of musculoskeletal problems and psychiatric disorders in family members during the year following the patient's cancer diagnosis. Family members' pre- and post-diagnosis health service use and costs, determined by medical records (n = 32), are presented in Table 3 and their diagnoses are presented in Figure 4.

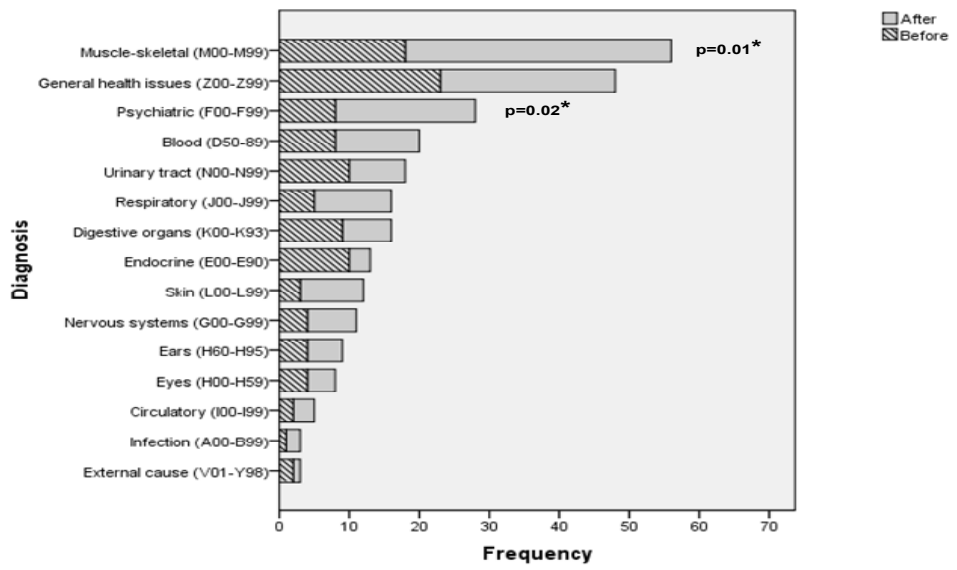


Figure 4. Family members' diagnoses during the year prior to and the year following the patient's cancer diagnosis (n=32)



## Cost of health service use

The results of the review of the family medical records (n = 32) showed that the family members had significantly more consultations with the physician during the year following the patient's cancer diagnosis than during the year before it (Table 3). The total cost of family members' health service use increased significantly during the post-diagnosis period. It was calculated on frequencies of inpatient hospital days and outpatient consultations (visits and telephone calls) with health-care professionals, including physicians' medical examinations with associated X-rays and laboratory tests. The total cost of health service use increased from the pre-diagnose (211,853 SEK = \$29,838) to the post-diagnose period (455,985 SEK = \$64,223) (Table 3).

Table 3. Family members' pre-diagnosis and post-diagnosis health service use and costs, determined by medical records (n = 32)

	<b>Pre-diagnosis period [12 months]</b>	<b>Post-diagnosis period [12 months]</b>	
	Frequencies	Frequencies	p-value
Out-patient contacts <sup>1</sup>	236	240	0.85
Out-patient physician contacts <sup>2</sup>	99	131	0.04
In-patient hospital days	0	10	#
Out-patient operations	0	5	#

	<b>Costs in Swedish krona (US dollar)</b>	<b>Costs in Swedish krona (US dollar)</b>	
Out-patient contacts <sup>3</sup>	211 853 (\$29 838)	287 341 (\$40 470)	<0.001
In-patient hospital days	0	115 468 (\$16 263)	#
Out-patient operations	0	53 176 (\$7 489)	#
Total costs	211 853 (\$29 838)	455 985 (\$64 223)	<0.001

Chi-squared tests were used to compare frequencies.

<sup>1</sup> Frequency of outpatient visits and phone calls with health professionals, including physicians' medical examinations with associated X-rays and lab tests.

<sup>2</sup> Frequency of visits and phone calls specifically with physicians, including medical examinations with associated X-rays and lab tests.

<sup>3</sup> Calculated based on costs of outpatient services

#not tested

## Health-related quality of life in family members of patients with an advanced cancer diagnosis: A one-year prospective study (Study II)

No statistically significant differences in HRQOL within the study group over the 1-year follow-up were found in physical or mental dimensions. However, compared with the norm-based scores as measured by the SF-36, the family members had significantly poorer mental HRQOL scores throughout the year. The mental HRQOL mean scores in Mental Component Summary, Vitality, Social Functioning, Role Emotional and Mental Health in SF-36 were significantly lowered ( $p < 0.05$ ), except for Role Emotional at assessment 4 (12 months after the diagnosis). Statistically significant differences were also found on the EQ-5D VAS in all five assessments as compared with the norm-based scores (Study II, Table 2 in Study II).

The age of the family members had a negative effect on the physical health dimension: family members aged 20–65 as compared with those aged 66–84 had statistically significant higher scores on the Physical Component Summary and Physical Functioning scale over the complete follow-up period in SF-36. Those in the younger age group were at higher risk for poorer mental HRQOL during the 1-year period, but the difference was only statistically significant at 3 months for the Mental Component Summary (Study II, Table 3 in Study II). In addition, being a partner had a negative influence on the physical dimension of HRQOL (Study II, Table 4 in Study II), especially on the Physical Component Summary Score and Physical Functioning scale throughout the 1-year period. The children had a statistically significant higher score at the 9, 12 and 15-month assessments, but had overall higher values or better HRQOL than the partners (Study II, Table 4 in Study II). However, most partners in the study (56%) were older (66–84 years), with worse scores on physical health possibly owing to physical fragility in older adults. The logistic regression analysis confirms that age had the greatest effect with regard to lower Physical Functioning scores, and age can therefore be seen as a confounder in respect of the explanation of the effect of the cancer diagnosis on family members.

## Striving to be prepared for the painful: Management strategies following a family member's diagnosis of advanced cancer (Study III)

The main findings are expressed through the overall theme, *Striving to be prepared for the painful*. Seven sub-themes were identified on the basis of the interviews. They cover management strategies that family members employ when the patient is in the early stage of treatment for advanced lung or gastrointestinal cancer. The sub-themes or management strategies are: (1) Making things easier in everyday life, (2) Banishing thoughts about the approaching loss, (3) Living in the present, (4) Adjusting to the sick person's situation, (5) Distracting oneself by being with others, (6) Shielding the family from grief and (7) Attempting to maintain hope.

The sub-theme *Making things easier in everyday life* concerns family members' efforts to make practical arrangements to make life easier for all in the changed family situation. They prepare and plan constantly so as to make things run smoothly in the stressfully daily life of the sick person. *Banishing thoughts about the approaching loss* is a way of managing the fear of the menacing future and trying not to think about it. There is no one who knows how long time the patient is going to live, and they try to cope with the stressful situation by distancing themselves emotionally. *Living in the present* involves avoiding to make plans for the future. They are aware that the sick person will die, but they do not know when it will happen. It thereby becomes more important for them to live in the present and make the most of life's good moments, instead of thinking about the future. *Adjusting to the sick person's situation* involves supporting the person as much as they are able to, day and night. They adapt to the sick person's situation and are always prepared to change their daily programme in accordance with his or her need for care. *Distracting oneself by being with others* involves trying to think about other things and forgetting for a while the difficulty of stressful daily life and the patient's suffering. It becomes important to be able to escape the difficult thoughts by distracting oneself through socializing in order to get new power and energy. *Shielding the family from grief* has to do with the difficulties to tell the family about the approaching death of the sick person. It becomes more important for family members not to say all

they know about the serious illness and prognosis. They want to prevent suffering for the family and bear the burden by themselves instead. *Attempting to maintain hope* involves hanging on to positive thoughts to make it easier to manage the menacing future. There may be hope in medical treatment despite the poor prognosis. The family members can focus on hope and faith in a shared future and forget the negative thoughts for a while. In sum, the findings revealed that the family members do what they can to make life easier, both for the sick person and for themselves. Visualizing their future life alone as a single parent or without their partner, they do what they can to make the most of the here and now for all involved — trying as it were, to carry the whole family in their arms.

## The meaning and validation of social networks for family members of persons with advanced cancer (Study IV)

The initial inductive analysis was resulted in nine sub-themes and one theme. Secondly, when the inductive analysis was completed, the findings were compared with Finfgeld-Connett conceptual model [4]. This model is based on a metasynthesis of previous research about social support and the comparison procedure was made in order to validate the findings. Three of the subthemes were classified as antecedents of social support, the other six as attributes of it. In the following text are each sub-theme first described sorted under antecedents or attributes and secondly presents the comparison between the findings and the concept model.

### Antecedents of social support

Three antecedents were identified for social support: *Need of support*, *Desire for a deeper relationship with relatives* and *Network to turn to*. *Need of support* represented an overwhelming despair brought about by a person in the family's having been diagnosed with advanced cancer. There was a great deal of psychological distress in the form of worry and sadness regarding the uncertain prognosis. *Desire for a deeper relationship with relatives* derived from a feeling of being estranged from certain relatives. The family members had had more contact with their relatives before the sick person's diagnosis than after it. They felt that the relatives had their own problems and for this reason were unable to

offer support. Not surprisingly, having a *Network to turn to* was an important source of support for the family members in their new situation. They could be together with others and talk about their sadness. When the family members could meet people in their network whenever they wanted they appreciated this very much and it gave them a sense of togetherness.

The validation of our findings with the model presented by Finfgeld-Connett [4] shows that two of the antecedents, *Need of support* and *Desire for a deeper relationship with relatives*, were linked closely to the antecedent Needs. The findings of the present study verified that the family members were aware of their need of support but felt that not all of their relatives were ready to provide such support. However, the third antecedent in the model, “Social climate” [4], was only implicitly embedded in the present study’s antecedent *Network to turn to*. “Social climate” may be most helpful if the persons involved have a shared context in which to anticipate, interpret and respond to the others’ needs [4].

### Attributes of social support

The theme *Confirmation through togetherness* summarizes the main findings of the inductive analysis. It is based on six sub-themes that explore the meaning of social support networks for close family of adult persons in the early stage of treatment for advanced lung or gastrointestinal cancer. The sub-themes which indicate the attributes of the meaning of social support are the following: *Understanding and support from relatives*, *Encouragement from neighbours and friends*, *Information and personal support from health-care staff*, *Involvement of fellow-workers and employer*, *Spiritual belief within a supportive community*, and *Greatest understanding from those who have experienced crises of their own*. *Understanding and support from relatives* gave emotional relief. The family members could talk about their feelings to someone who knew what the situation was. Their relatives provided practical assistance with things like child-minding, housekeeping and gardening, and it was a great relief not to have to worry about these things. Participants felt it was essential to have their closest relatives near at hand. *Encouragement from neighbours and friends* supported the family members in their stressful daily life. The spontaneous chat gave them a sense of belonging to the community. The encouragement made them calmer in the face of a menacing future and the worry about the sick person. Receiving

*information and personal support from health-care staff* was important to the family members. They appreciated receiving information about diagnosis and treatment. They perceived that the staff cared and gave them the information direct. *Involvement of fellow-workers and employer* was a source of support for the family members. The daily chat with the fellow-workers gave them the chance to forget their problems for a little while. The employer did everything to help them and adapted their work schedule when they needed to go to the hospital with the sick person. *Spiritual belief within a supportive community* was a further source of support. The meetings at church with their friends gave them a sense of community. Their faith helped them to confront the menacing future. Finally, there is the sub-theme *Greatest understanding from those who have experienced crises of their own*. Such people knew what the family member was going through, knew the burden of being in such a precarious situation. The understanding from these people gave the family members the strength to manage the situation by expressing feelings.

In contrast with attributes of social support in the Finfgeld-Connett metasynthesis, the theme contains two keywords. Confirmation is usually expressed in the literature in terms of affirmation or validation, whilst togetherness was not identified in the metasynthesis at all [4]. Most of the keywords of the sub-themes are to be found in the metasynthesis as attributes of social support [4]. The metasynthesis shows that social support involves the reciprocal exchange of verbal or/and nonverbal (flowers, cards, eye movements, facial expressions) information that is characterized by advocacy. Information consists of facts, advice, words of reassurance, positive affirmation and empathy. Encouragement is a common advocative strategy employed in an unconditionally positive atmosphere. Spiritual belief systems are sometimes considered to be part of social support networks but authors provide little explanation of this phenomenon [4]. However, there were two keywords of the subthemes that did not emerge in the metasynthesis, namely understanding and involvement. Among the Outcomes in improved mental health to be found in the metasynthesis [4] occur the outcomes of social support in a broad sense of improved mental health in large part as increased sense of personal competence, experiences of empowerment and an enhanced sense of reassurance. This means a sense of well-being and diminished distress.

## Discussion

The most frequently reported type of social support given by the family members to the cancer patients was emotional, which might be explained by the seriousness of the diagnosis (Study I). The estimated average number of hours spent providing functional support was 4 per day or 1,702 over a period of 15 months after the diagnosis (Study I). If professional caregivers had provided this support, it would be equivalent to an average cost per person of SEK 718 per day or 327,000 SEK over the 15 months, amounting to SEK 11,772 000 for the whole group (n=36) (Study I). The number of hours spent on providing such support may have influenced the family members' lower mental scores in HRQOL on the SF-36 (Study II), suggesting that this effort involves a major burden on the caregiver and thereby increased risk of ill health and reduced working capacity. This hypothesis is supported by the increased frequency of psychiatric and musculoskeletal disorders (Study I, Table 7). Another stressful factor for the caregivers is awareness of the seriousness of the disease and its uncertain outcome. The results indeed indicate that the distressing period after diagnosis may be of significance for the family members' frequency of health care utilization.

The results show also a small increase in the number of inpatient hospital days and outpatient physician consultations (Study I). The family member is faced with a very difficult situation with an uncertain future, and in fact 57 of the family members who initially participated (Studies I-II) had a relative who died within fifteen months of the diagnosis. This is in line with the prognosis of high mortality rates associated with these cancer diagnoses [10]. Lung and stomach cancer are two of the four most common cancers with a high mortality rate in Europe [135]. This suggests that quite a large proportion of family members of persons diagnosed as having cancer end up in a situation that is difficult and requires good coping strategies. However, family members do have relatively efficient coping strategies for the early stages following a person's being diagnosed as having advanced cancer. The period soon after diagnosis was characterized by fear and the threat of death among the family members in our study, and they were *Striving to be prepared for the painful* (Study III). They made practical arrangements to make life easier

for all in the changed family situation, planning constantly so as to make things run smoothly from day to day. They had hope for the future and they handled the present by taking one day at a time (Study III). Most of them had a supporting social network with *Confirmation through togetherness*. *Need of support*, *Desire for a deeper relationship with relatives* and *Network to turn to* were the antecedents of social support. Social support involves reciprocal exchange of verbal and non-verbal information provided mainly by lay persons. If health-care professionals focus on family members' personal networks by using a measuring instrument this could strengthen the family members' mental health (Study IV). It is conceivable that the ability to manage the difficult situation and having the social network to turn to can explain the modest increased frequency of psychiatric and musculo-skeletal disorders (Study I, Table 7). However, the results do suggest a modest deterioration of health at the group level, and the dispersion indicates that there are families at the margin who experienced a very difficult situation. For these people, there is a high risk of illness and thus reduced ability to provide informal caregiving of high quality.

One of the most common types of support provided by the informal caregivers in the study conducted by the National Board of Health and Welfare (NBHW) [18] involved socializing and stimulus. Most prominent in our study was emotional support, followed by practical support in household work (Study I). The presence of practical support is consistent with the NBHW results. In our study the informal caregivers themselves set the number of hours they had spent on every type of support. In the NBHW study they chose among predetermined proposed alternatives. The most frequently chosen alternative was extensive caregiving (1–10 hours per week), followed by very extensive caregiving (11+ hours per week) [18]. The average number of hours spent providing support in our study (Study I) was estimated as being 4 hours per day or 28 per week per individual, which means very extensive informal caregiving. This can be explained by the fact that the family members in our study gave support to persons who had an advanced cancer diagnosis and thereby a greater need for support (Study I) than the heterogeneous patient group selected from the Swedish population [18].



The family members had below-normal scores on the mental dimension of HRQOL, indicating they felt worse than the general population (Study II, Table 2). This, together with the increased number of physician consultations during the year following the patient's cancer diagnosis, indicates that there is a risk of increased morbidity (Study I, Table 5). The effect of informal caregiving on mental health has been well described in the literature [38, 137, 138], less so the effect on physical health [55, 56, 107].

Older age had a negative effect on the physical dimensions of HRQOL in our study (Study II, Table 3). Previous research shows that informal caregiving is a risk factor for mortality in older family members [138] and shows negative effects on the immune system with increased prevalence of both infectious diseases and auto-immune diseases in older age [139-141]. Since there are very few studies about cancer's impact on family caregivers' physical health, the results of this study need to be set against those of large-scale studies [55, 56, 107]. The National Board of Health and Welfare study [18] shows a negative correlation between the extent of care and self-rated health. More caregiving means worse health for the caregivers. Caregivers 25-64 years old reported poorer health than the same age group in the total population. In contrast, caregivers 65-84 years old reported better health than the same age group in the total population. Only those older persons who provide extensive care reached the same level of health as in the general population. Even taking age into account, there is a negative correlation between the extent of caregiving and the caregiver's self-rated health [18]. Caregiving can be a great burden for the family members, with risk of illness and thus reduced ability to provide support. There is a risk of additional burden if the health-care staff thinks that family members should provide more informal caregiving for the sick person in times of economic austerity.

The estimated cost of health-care utilization in our study increased significantly during the post-diagnosis period as compared with the year before the diagnosis. We could find no published study about the costs of informal caregivers' health-care utilization in the context of cancer care. However, the costs of cancer care have been increasing [147]. One explanation of the increase in the number of persons diagnosed with cancer is the ageing population [5]. In Study I the older

caregivers were mostly partners who lived with the patient (Study II). They had a vital role in informal caregiving as the patient's closest support person [31, 45, 144]. This burden in informal caregiving could very well also increase the number of medical visits. The family members had significantly more physician consultations during the year following the patient's cancer diagnosis than during the year before the diagnosis (Study I). Informal caregivers are mostly providing support in the care of older people [148]. Cancer incidence rates in Sweden have increased over the past 30 years, and this is expected to continue because of demographic changes [146]. Currently, Sweden has one of the oldest populations in the world, and it is estimated that in 2030 about 23 per cent of the population will be older than 65 [170].

Mostly the family members did not report refraining from weekly leisure activities as a result of providing support for the sick person in Study I. The study I contains no information about the informal caregiver's own valuation of lost time and leisure in terms of money [61, 151]. However, the average number of hours of absence from work during the post-diagnosis period was estimated as 4,369 for the whole study group and 121 per caregiver (Study I). This may be seen as a reasonable result in that only about 40 per cent of the informal caregivers (n=14) in our study (Study I) were working and the informal caregiving had not had a great effect on their attendance at work. A further possible explanation of the low estimated average hours of absence from work in our study (Study I) is that the informal caregivers have adapted their working hours to the informal caregiving, this on the basis of flexible hours and compensatory time. Had the informal caregivers in our study been mostly of working age, the number of hours of support provided might have been different. In a study by Sand [152] of informal caregivers who combine paid work and informal caregiving it emerged that about 75 per cent of all caregiving was performed by family members and relatives, which is more than in the past. In recent years, however, cuts in health-care services in Sweden have been, so to speak, passed on to the family. Family members' assumption of caregiving responsibility is seen as a voluntary, private matter that should be encouraged and supported. Economic benefits, to the extent that they are given, rarely correspond to salary from gainful employment and are no real alternative for those who need to reduce their working hours to cope with caregiving [152]. The

absence from work during the previous week for the family members (Study I) was estimated by multiplying the hours by the average hourly wage of a home health care assistant, including calculation of holiday pay and social contributions [128]. The average cost of absence from work (Study I) was SEK 23,232 (\$3,272) over the fifteen-month period following the cancer diagnosis. Today the cost of loss of productivity is greater than the direct medical cost of cancer [180]. The results in Study I of the estimation of the hours of absence from work need to be further investigated, especially in respect of informal caregivers of working age.

Our findings in Study III showed that the family members' management strategies could be expressed by the theme *Striving to be prepared for the painful*. The previous studies had shown that the family members were overwhelmed by the sense of a tragic future, knowing that a great loss was approaching [44, 153, 154]. The informal caregivers were subject to extremely stressful emotions because of the uncertainty of the future where the life or physical integrity of the loved-one was threatened [136, 165]. A life-threatening illness may trigger a change in the quality of the relationship between family members and the sick person [155]. Family members often need help in managing such a situation [8]. In a study performed by Persson and Sundin [28] the significant others were found to be "Striving to function oneself" as best they could in everyday life whilst also attempting to visualize what the future held in store through "Managing perceived threats" [28]. The family members try to make things easier by making practical changes for themselves and their families in everyday life (Study III). A similar strategy was reported previously and expressed as "make the best of it" [154]. In a study by Pusa and colleagues the family members are moving forwards and making adjustments in everyday life, finding new ways to manage the situation [156]. It is a here question of not giving up, of being strong, looking ahead and doing all that is possible to solve practical problems. Problem-focused coping strategies are concerned with handling the source of stress, dealing directly with the situation. This type of coping is related to problem-solving and is more often successful than emotion-focused coping [157]. Making things easier in everyday life is classified as problem-focused coping. The other coping strategies were emotion-focused (Study III). These are concerned with handling emotions associated with

stressful situations, (i.e. relieving the feeling of stress without actually having to change the situation) [81, 82].

The family members are *Striving to be prepared for the painful* and at the same time they are attempting to *Maintain hope*. Setting hopes on the future was the strategy least frequently mentioned by the family members in the interviews. One possible explanation for this is that the cancer diagnosis had been received two or three months ago, and some family members might have still been in shock or might at least not yet have adjusted to the new reality of the person's having advanced cancer. Living in the present helped the family members to carry on from day to day, and the hope made it easier to deal with the frightening future (Study III).

The meaning or main attribute of the social support network for the family member was expressed by the theme *Confirmation through togetherness*, based on six subthemes derived principally from information, understanding, encouragement, involvement and spiritual community (Study IV). Confirmation lightened the distress and made it easier to deal with the situation, as has also been shown in previous studies [161, 162]. Finfgeld-Connett [4] established that the need for social support has a psychosocial substratum, which was verified in the present study through the antecedents *Need of support*, *Desire for a deeper relationship with relatives* and *Network to turn to*. The family members expressed a great deal of psychological distress in the form of worry and sadness regarding the uncertain prognosis. They family were in need of support because of their overwhelming despair when faced with the fact that one of them had been diagnosed as having advanced cancer (Study IV). Nursing intervention needs to bolster existing networks or to promote the development of new ones [4]. A study by Henriksson and colleagues [160] has shown that support group programmes for family members during ongoing palliative care strengthens the sense of confirmation and sense of belonging [160]. Perhaps there is also a role for Internet-based support in the fulfilment of the caregivers' needs, especially their emotional ones [164].

It is important that the health-care staff be able to identify the needs of the patient and the family members in the early stage after diagnosis and that they

inform families about the possibility of support. It is therefore important that the county council and the municipality work together [18, 158, 167]. Especially collaboration between social services and primary health-care services needs to be developed [13, 181]. Municipalities can offer respite care in different forms, so that family members can have their own free time. Municipal health services should offer individually tailored support to informal caregivers, involving respect, reassurance and co-operation, in line with the Social Services Act [2, 142, 163]. Few people know who to contact or know about the legislation concerning the possibilities of help and support [18]. The caregiving of informal caregivers for the relatives has an important societal function. Without the informal caregivers' assumption of the responsibilities, society would not be able to meet citizens' needs for support [13, 159].

Another step is to develop instruments for use in the evaluation of non-professional social support. Developing measurement instruments [89] could encourage nurses and other health-care professionals to focus on family members' personal networks as a way to strengthen mental health. Nurses should recognize the support offered by a social network as a particular part of the nursing intervention, and differentiate the concept of social support from concepts such as caring [89]. Health-care professionals need to encourage informal caregivers to use and enhance personal support networks, as this may have a positive effect on coping and mental well-being. If the cancer patients do not have the support from the family members there may be a great increase in the number of hours and thereby the cost of support from professional caregivers.

In addition, it is important that health-care staff should provide information and support personally to family members (Study IV). Interestingly, it was found that family members did not expect to be supported primarily by health-care staff even though this is in fact a part of the staff's duties (Study IV). In a study by Astedt-Kurki and colleagues [166] the health care staff expects the family member to contact staff regarding information about the patient [179]. In a study by Olsson the findings showed that professional health-care staff who attempts to become too close or too warm emotionally may be rejected by the family members [70]. Another thing is that staff does not always see themselves as

being expected to provide emotional support. In a study by Christensson and colleagues [182] investigating attitudes of different professionals, nursing assistants agreed significantly more with the statement “It is not the duty of the staff to take care of a relative who is in need of support” than did registered nurses. Health-care staff provided social support only when relatives could not get the requisite support from their networks [182]. Furthermore staff considered that it was up to the family member to get in touch with them regarding information about the person with cancer and regarding the family member’s responsibility for the home care [182].

The Health and Medical Services Act [105] decrees that the family members shall have the opportunity to participate in the formal caregiving. In a press release by Maria Larsson, the Minister of Elderly Care and Public Health [167], about the new Government bill [163], it was stressed that family members should not be compelled to provide informal caregiving but that those who provided it of their own free will should be given the proper support. The family members shall not become physically and mentally worn-out. The goal is that both the family members and those for whom they provide care shall feel more secure [167]. Most common is that the support given to family members by health-care and social services is in the form of offering them the opportunity to participate in the health care of the sick person [13]. It has been stated by the National Board of Health and Welfare that informal caregivers at present bear too much responsibility and that the public sector should assume the main responsibility [18]. The economic cost of cancer was 34 billion in 2009 and is expected to increase to 70 billion by 2030 [7]. There is a risk that the health-care authorities will think that family members should do more informal caregiving in times of economic austerity. However, the increase in the size of the aged population needs to be considered, which also includes family members.

## Summary of main results

- The family members providing informal caregiving were mostly partners and females. The most common support was emotional, followed by functional support with household work (Study I).
- The average number of hours spent providing support during one year was estimated at 4 per day (Study I). If professional caregivers such as home help care assistants had provided this support, it would be equivalent to a cost of SEK 718 per day or 327,000 per 15 months (Study I).
- A review of medical records showed an increased morbidity among the family members, mainly in terms of psychiatric diagnoses and musculoskeletal diseases. Also, the family members had a greater need of health services (e.g. physician consultations) during the year after the cancer diagnosis than during the year preceding it (Study I).
- The scores on the mental dimensions of HRQOL, as measured with SF-36, were lower than the norm-based ones during the follow-up period (Study II). Younger family members were a more vulnerable group regarding mental health (Study II).
- Old age implied a higher risk of decreased physical HRQOL, particularly if the informal caregiver was a partner (Study II).
- Family members managed the threatening future by striving to be prepared for the painful (Study III).
- Emotion-focused coping strategies were used most, except for the problem-focused coping strategy of making things easier in everyday life both for the sick person and for themselves. The partners anticipated that they were going to be left alone as single partners and tried to carry the whole family in their arms (Study III).
- The family members experienced themselves as being members of their communities. *Confirmation through togetherness* expresses the support they received from their social networks, indicating a more equal relationship than in a care relationship with health-care professionals (Study IV).
- *Need of support*, *Desire for a deeper relationship with relatives* and *Network to turn to* were identified as aspects of antecedents of social support. Mostly the family members reported positive experiences in

respect of close relatives, nevertheless there were relatives who shied away from the troublesome situation, and the family members desired a deeper relationship with these relatives (Study IV).

## **Methodological Considerations**

The strength of this thesis comes from the use of quantitative and qualitative approaches in tandem, embedded one in the other — thereby overcoming the weaknesses of both methods and giving both breadth and depth through information from statistical results and narratives to provide new insights and refined thinking [112]. The analyses are performed separately in this mixed-method design and complement each other [112]. This for a more complete understanding of the consequences of caregiving for the family of patients diagnosed with advanced lung or gastrointestinal cancer over a one-year period, including their management of their trying daily life and the meaning of the social support network in the early stage .

### **Quantitative studies**

#### **Design (Studies I-II)**

The prospective design in Studies I-II [168] was appropriate for studying the variables over time given that the patients' cancer progresses rapidly and may affect the family members [168]. The 1-year follow-up period was considered appropriate in respect of investigating outcomes for family members, because of the mortality rate of advanced cancer patients (Studies I-II). The prospective design (Studies I-II) is also a condition for being able to investigate whether there is a causal connection between being a caregiver, health and health-related quality of life. For a caregiver knowing that a family member has cancer and expects aid, means for many increased mental and physical strain. This, it was found, can lead to impaired health-related quality of life and health, which is reasonable to expect and in line with the findings of other studies [169]. But there is also a weakness in that the strength of the relationship has not been



analysed statistically, for which reason it is not possible to comment with any confidence on what happens to health and health-related quality if the mental and physical load increases or decreases. Nevertheless there would seem to be good reason to believe that there is indeed a causal connection between being a caregiver, health and health-related quality of life [18] (Studies I-II).

There is no single way to best value caregivers' time [76] or single source of comprehensive health-care utilization. Administrative data sources of health-care utilization are usually considered to be the most accurate, but their use is limited because caregiving by family members is not systematically captured in decentralized health-care systems [77]. Therefore, in Study I we used multiple data sources in order to obtain a comprehensive and valid picture of what the provision of informal caregiving cost the family members, not only financially but also in terms both of time and of their own health and health-care utilization (Study I).

### ***Participants (Studies I-II)***

At the start of data collection in September 2007 the availability of family members providing caregiving for persons with lung cancer was insufficient for our purposes, therefore the inclusion criterion was changed to also include persons with cancer of the gastrointestinal tract. Furthermore the data collection period was expanded from two to three years in order to obtain the calculated group size. In addition there were drop-outs both before the start and during the study (Studies I- II). The selection of family members was accomplished firstly with the assistance of staff (nurses and physicians), who asked the patients about participation in the study, secondly with the assistance of the patients themselves, who asked their family members about participation. This procedure explains why there is no information about the reasons for drop-outs and why there are no demographic data in respect of the family members who declined participation, apart from the 21 family members in Study II. However, there are two stages where drop-out may occurred: either patients changed their minds and did not pass on the information letter to family members, or family members did not fill in the reply slip on the letter. The initial recruitment could have been done differently. The initial number who dropped out might have been reduced

if the family members had been approached personally by the researcher or only one nurse at each hospital. Furthermore, in studies of this type involving informal caregivers a large drop-out is relatively common. To give but one example, a National Board of Health and Welfare study involving 15 000 randomly chosen members of the population 18 years or older had a drop-out of 45 per cent [18]. This meant that there was a great risk that the loss was not randomly distributed. Moreover, it was not known whether the 55 per cent who responded were representative of the population as a whole. Of these persons, only 1,513 gave care, which is 18 per cent [18]. However, it can be difficult to compare results from different studies, as there are differences in approach, selection and drop-outs.

Of the 57 family members initially participating in this study, only 36 participated in all five data collections — this despite several reminders during the data collection procedure in order to prevent drop-outs. Analysis of the drop-out showed that the 21 family members who dropped out during the study were not significantly different in age, gender, education, occupation or relationship from those who completed the study. In addition, a strength of the data is that there was no difference in HRQOL or EQ-5D at baseline between the drop-outs and those who participated in all five data collections. A reason for the low statistical power [183] was our decision to include only family members who filled in the questionnaires in all five data collections (Studies I-II). It was considered better to compare the same persons over time than to compare groups the size of which differed because of drop-out. The drop-out during the study was attributable to the increased sickness of the patients, a factor that was out of our control during the year-long data collection. This reason for drop-out has been previously described in the literature in respect of patients with severe or advanced cancer [27, 184]. However, the large non-response rate makes the study's generalizability uncertain, which must be kept in mind when interpreting the results (Studies I-II).

## Analysis (Studies I-II)

Valid and reliable measurement of health-service utilization, productivity loss and thus total disease-related costs is a prerequisite for health-service research

and health-economic analysis (Study I). Health-economic evaluation should involve not only quantifiable, financial costs but also intangible ones, difficult to evaluate in terms of money. Such evaluation is aimed essentially at improving decision-making and cost-effectiveness [171]. Health-economic analyses form a basis for decision-making in health care [172], a basis for allocating limited resources where they are most useful. Typically, the goal of the analysis is formulated from a societal perspective, but the costs and effects for the family members of a patient with a disease should be included in the analysis. The societal costs of dementia and other diseases have been estimated in a study from the National Board of Health and Welfare [173] in which informal caregivers' costs were included. The study showed that the social costs of dementia were greater than those of cancer [173]. It is difficult, in health-economic studies, to make a full-scale estimate of costs and effects in the case of informal caregivers [61, 74, 150]. Nevertheless, estimation of the cost of informal caregiving using the proxy good method can be incorporated in common types of economic valuation [174]. Double calculation is not a major problem in using the proxy good method, since the estimate is based on the informal caregiver's perspective. The opportunity cost method is recommended as the better method when the informal caregiver time is valued in terms of the person's best use of time [75, 174]. This study used the wage rate for equivalent service (i.e. that provided by a home health care assistant) as an estimate of the plausible cost of the time devoted to caregiving. Both absence from work and refraining from usual activities during the past week were included in the data concerning the family members' caregiving. However, the questionnaire was developed specifically for this study and was being used for the first time, which should be considered when interpreting the results. There is a need for a questionnaire and other effective methods with good validity to use across diagnoses and health-care systems in further studies [185]. The costs of support and health care estimated in our study cannot be routinely generalized to other countries because of differences in costs, salaries and health-care systems. Though comparison of the numbers of hours spent providing support and numbers of health-service consultations is more valid, the fact remains that differences in resource availability and health-care accessibility can influence the frequency of utilization of hospital consultations [185] (Study I).

In Study II the small number of family members resulted in low statistical power and therefore less opportunity to detect small changes over time and differences between subgroups in the study population. This in spite of our recruitment of family members from two medium-sized hospitals and quite a long inclusion period (2007–2010). Furthermore the logistic regression analysis which was performed should be considered from a descriptive perspective; it did not include type of relationship in respect of HRQOL, because of a large difference in group size (partners,  $n = 28$ ; children,  $n = 8$ ). The ability to predict values was relatively low in respect of the children (50–62% correct) as compared with the partners (83%) and age (85%).

Furthermore the selection method may explain the skewed dispersion in the study material with a low proportion of men despite the fact that both physicians and nurses (representing both sexes) asked the family members whether they would participate in the study. However, 26 of the 36 patients who asked one of their family members to participate were males (72%), and 20 of them (77%) chose a female partner. Six of the males chose a grown child, and five of those were daughters. Cancer incidence and mortality in Europe predominately involves men with lung or upper gastrointestinal tract cancer [10]. These cancer diagnoses are also the most common worldwide among men and constitute 42% of new cases and 48% of total cancer deaths. Given that a diagnosis of lung or upper gastrointestinal tract cancer is more common among men, it seems reasonable that our study group comprised predominately male cancer patients and female family members.

When a large number of comparisons are statistically examined, there is a risk of mass significance. With an alpha level of 0.05, the risk of random significance is 1 in 20. One way to diminish the risk of mass significance is to lower the alpha level. Procedures used to calculate a new alpha level are Bonferroni's test and the Dunn-Sidak correction [183]. However, in the case of this study we considered that these tests would be too conservative and might increase the possibility of a type II statistical error. For this reason, weak or solitary significances should be considered with some skepticism. Furthermore, the collected data are ordinal-level and not equidistant, thus there is a risk of bias in

evaluating the size of changes [175] owing to the uneven distribution of such changes.

Conclusions concerning our results are therefore based on the patterns of significant differences that were in the same direction without deviant values. Linear mixed models [176] can be used to describe nonlinear relationships across time in a longitudinal dataset. The strengths of the linear mixed models are the ability to accommodate missing data points and the ability to model nonlinear, individual characteristics [176]. The linear mixed model emphasizes patterns of change and individual differences and assumes not a normal distribution but instead systematic change (Study II).

## Qualitative studies

Qualitative studies are usually evaluated in terms of trustworthiness, comprising credibility, dependability and transferability [177].

### Credibility (Studies III-IV)

Credibility is used to check that the data, data collection, analysis and design were used in a proper way. The family members in this study appreciated being able to talk about their situation, and the interviews were characterized by richness of narration [177, 178]. The achievement of credibility in the inductive approach to qualitative content analysis in this study implies careful and comprehensive interpretation at every stage of the research process [131]. The basic principles of latent content analysis were applied, which means that there was systematic coding into sub-themes and then integration into a theme [131] (Studies III-IV). Experienced researchers with knowledge of latent content analysis checked the credibility (Studies III-IV). The credibility of the inductive analysis in Study IV was strengthened by means of comparing the sub-themes and the theme with concepts in the previous meta-synthesis based on 44 qualitative studies [131]. The findings added three attributes to the previous model. Furthermore, the interview questions in Study IV were not constructed to capture the aspects of antecedents and outcomes of social support, therefore — not unexpectedly — our findings were not related to the aspects of the

antecedent *Social climate* and the outcome *Improved mental health*. This must be kept in mind when comparing the results of the present study with the conceptual analysis of Finfgeld-Connett [4] (Study IV). It is possible that the family member chosen to participate was not the one most dissatisfied with their social network. This can explain the finding that only a few family members expressed the need of deeper contact with close relatives in their social network.

### Dependability (Studies III-IV)

Dependability shows the stability of data [177, 178] and was ensured by asking the family members the same main questions in accordance with the interview guide in Studies III-IV [178]. The interviews were listened to and the text read several times to confirm that the transcription was correct. The text was read and checked in all steps by researchers experienced in qualitative analysis. The family members in Studies III-IV were not experiencing high caring demands, as the patients were in the early stage of the illness trajectory. A longer period of illness often means a greater amount of caregiving to the relative with advanced cancer and as a consequence more isolation, both for the family members and the patient [186].

### Transferability (Studies III-IV)

Transferability concerns the possibility of carrying the findings over to other contexts [177, 178]. Studies III-IV comprises two cross-sectional studies of family members who are faced with having an adult relative with cancer in the early stage of treatment. Previous studies have, with few exceptions, concerned a later stage of palliative or terminal care. Our findings should only be transferred to family members in a similar context. One weakness with regard to the transferability of the findings is the small proportion of male participants also in the interview studies. It is possible that the family member chosen to participate was not the one most dissatisfied with their social support. This needs to be kept in mind when comparing the findings in this study with findings in previous research. Gratitude on the part of the family member regarding the possibility of the patient's receiving curative treatment, as well as deep respect for the health-care professionals' commitment to helping the patient, may also have influenced the findings (Studies III-IV).

## Conclusions

Family members seem to have adapted management strategies for handling their situation in the early stages after the cancer diagnosis, mostly with support from their social network. Despite these management strategies, however, the family members as informal caregivers may develop a risk of morbidity, with increased health service use and increased musculoskeletal problems and psychiatric diagnoses during the year following the cancer diagnosis. Whilst the fact that a large proportion of caregiving is provided by family members is positive — indeed invaluable — from a societal perspective (cutting as it does the cost of caregiving provided by health-care staff), it is negative in that it causes increased morbidity among the family members, involving in the first place their suffering but also costs in terms of loss of productivity in their work and greater health-care utilization on their part. The persons diagnosed with cancer were seriously ill and had a high mortality rate, which suggests that the family members were living with a mentally stressful situation. Especially the older family members and partners were at higher risk for decreased physical HRQOL throughout the year following the diagnosis, and younger family members were at higher risk for decreased mental HRQOL. Therefore health-care staff needs to pay close attention to each family member both as a person assuming the role of informal caregiver and as a person with particular needs. In supporting the family member as an informal caregiver and as an individual, staff can also be indirectly enhancing the care of the person diagnosed with advanced cancer.

## Clinical and research implications

In terms of clinical relevance, the findings concerning decreased mental HRQOL among family of persons with advanced cancer highlight how important it is that nurses, physicians and other health-care professionals should provide supportive measures integrated into treatment and care. The informal caregivers' risk of morbidity, with increased health service use and increased musculoskeletal problems and psychiatric troubles during the year following the diagnosis, indicates a need to develop guidelines for preventing ill-health. We require more knowledge about how individually tailored

support best can be given to reduce the risk of morbidity. There is a need for evidence-based intervention programmes that prevent ill-health and for identifying the caregivers who are most vulnerable. There is also a need to develop a measurement instruments that could encourage nurses, physicians and other health-care professionals to focus on caregivers' personal networks as a way to strengthen their mental health. Family members should be offered support at an early stage to reduce their mental and physical distress. A greater focus on preventive measures will lead to improved treatment and reduced suffering, benefiting both the cancer patients and their caregivers. The provision of support for informal caregivers requires strategies for developing support programmes involving collaboration at both the county and the municipal level. The health and social services need to design a form of support for informal caregivers best-suited to preventing illness among them and enhancing their ability to cope.

There is an urgent need to develop support interventions for family members as caregivers of seriously ill cancer patients to prevent suffering and unnecessary health-service costs. The main contribution of this thesis is to indicate how much the cost to society would most likely have been if the cancer patients had not had the support of their caregivers but had been dependent on professional caregivers instead. There is need for further investigation of the costs identified, including costs of family members' morbidity, health-service utilization and absence from work. The costs of the cancer care will increase as the informal caregivers grow older and perhaps become less able to provide caregiving. Further longitudinal research with a larger study group is needed with regard to the family members' increased risk of ill-health, as well as their experiences of providing informal caregiving for a relative with cancer.



# Swedish Summary

## Bakgrund

Denna avhandling handlar om anhöriga till personer med lung och gastrointerstinal cancer. Personer som insjuknar i cancer har ökat de senaste 20 åren beroende på fler screening undersökningar, förbättrade diagnostiska metoder och effektivare behandlingar samt en åldrande befolkning. Anhöriga ger stöd till personen med cancer under sjukdomsprogressen och alltmer av vården och den medicinska behandlingen sker i patientens hem. Att leva tillsammans med en person med cancer innebär både en fysisk och mental påfrestning i vardagen. Anhöriga som ger vård till personer med cancer försöker hantera sin svåra situation på olika sätt. Det är därför viktigt att få veta mera om anhörigas uppföringar och om deras situation samt om hälsan påverkas av det stöd och den vård de ger till den cancersjuka. Det finns ett antal studier som har undersökt effekten på anhörigas mentala hälsa men endast ett fåtal om den fysiska hälsan.

Ökad kunskap om anhörigas situation strax efter diagnostillfället och under året efter kan ge bättre möjligheter att förstå hur ett förebyggande program som innefattar anhöriga kan utformas initialt och senare under sjukdomsförloppet. Att studera anhörigas hälsa över tid och identifiera kostnader för hälso- och sjukvården som uppstår som en konsekvens av att vara anhörigvårdare är ett viktigt bidrag till ett kunskapsunderlag. Mer fokus på förebyggande insatser kan bidra till ökat välbefinnande för både anhöriga och personer med cancersjukdom. Ökade kunskaper behövs om följderna av anhörigvård för anhöriges egen hälsa, hälsorelaterade livskvalitet, sjukvårdskostnader, egna kostnader och hanteringsstrategier samt stöd som anhöriga får av sitt egna informella nätverk. Resultaten från denna avhandling kan bidra till förbättrat kunskapsunderlag för vårdpersonal för att erbjuda individuell och adekvat hjälp och stöd till anhörigvårdare utifrån var och ens förutsättningar.

## Avhandlingens övergripande syfte

Det övergripande syftet med avhandlingen är att undersöka konsekvenserna av att vara anhöriga till personer med cancer i lunga eller övre mag-tarm kanalen under en tidsperiod av ett år, innefattande deras hälsa, hälsorelaterad livskvalitet, vårdkonsumtion och tillhörande kostnader. För att få en djupare förståelse för deras livssituation undersöktes även anhörigas strategier för att hantera deras vardag samt betydelsen av socialt stöd i ett tidigt skede av sjukdomsförloppet.

## Metod

Avhandlingen består av två studier med jämförande, prospektiv kvantitativ design (studie I-II) och två tvärsnittsstudier med induktiv kvalitativ design (III-IV). Studie I omfattar året före patientens cancer diagnos och året efter, medan Studie II omfattar året efter diagnosen. Studie III och IV består av kvalitativa intervjuer i ett tidigt skede av sjukdomsförloppet. I Studie IV validerades också resultaten mot begrepp från en meta-syntes publicerad av Finfgeld-Connett [4]. Datainsamlingen för de fyra studierna påbörjades vid samma tidpunkt med tillämpning av samma urvalskriterier, men där olika antal anhöriga ingick i de olika studierna.

De anhöriga som ingick i studie I-IV var familjemedlemmar till personer 18 år eller äldre med diagnostiserad cancersjukdom i lung eller övre mag-tarmkanalen inom de tre senaste månaderna. Sjuksköterskor och läkare vid en medicinsk och två kirurgiska kliniker på två sjukhus i ett landsting med ett upptagningsområde om 337 000 invånare tillfrågade personer med cancersjukdom om de ville efterhöra med en anhörig om deras intresse för deltagande i forskningsprojektet. Patienten fick ett eget informationsbrev om syftet med studien och ett informationsbrev till sin anhörig. Den cancersjuka personen valde själv vilken anhörig som skulle tillfrågas. Den av patienten tillfrågade anhörige skickade svarstalong till projektledare med sitt samtycke och projektledare tog därefter telefonkontakt med den anhörige. Antalet anhöriga som eftersträvades var 60 personer vilket uppnåddes efter att 200 personer med cancersjukdom tillfrågats. Målet var att studiegruppens storlek skulle ge en acceptabel statistisk

styrka för de två kvantitativa studierna. Datainsamlingen genomfördes under tidsperioden september 2007 till och med maj 2011.

## Avhandlingens studier

### Delstudie I

Syftet med studie I var att undersöka vilken typ av socialt stöd som anhöriga ger till de cancersjuka, uppskatta konsekvenserna av deras insatser som informell anhängigvårdare genom att studera sjuklighet och ekonomiska kostnader som följd av vårdskonsumtion och informell vård. Den mest vanliga formen av stöd som familjemedlemmar gav var känslomässigt stöd (54 %). Det genomsnittliga antalet timmar uppgick till 926 timmar under ett år. Det näst vanligaste stödet var hushållsarbete (26 %) med 444 timmar. Det höga genomsnittliga antalet timmar i känslomässigt stöd kan förklaras av att familjemedlemmarna gav stöd i en för personen med cancer kritisk situation. Mer än hälften av de anhöriga (30 av 57) som initialt deltog i studien hade en släkting som dog inom femton månader från cancerdiagnosen. Beräknad kostnad för det genomsnittliga skattade antalet timmar för socialt stöd uppgick till 327 000 kronor. För känslomässigt stöd beräknades kostnaden till 178 000 kronor och hushållsarbete 85 000 kronor.

Det genomsnittliga antalet timmar som anhörig var borta från arbetet för att ge stöd/vård till sin släkting uppskattades till 121 timmar för varje familjemedlem och 4 369 timmar för hela undersökningsgruppen under året. Den totala kostnaden för frånvaro från arbetet beräknades till 838 848 kronor. Mestadels rapporterade inte de anhöriga att de avstod från andra aktiviteter för att ge stöd/vård.

Anhörigas sjuklighet (n=32) ökade ett år efter i jämförelse med ett år innan cancer diagnos. Sjukligheten identifierades via medicinska journaler i antal vårdkontakter, antal läkarbesök och diagnoser. Antalet läkarbesök ökade signifikant liksom antalet muskuloskeletala och psykiska diagnoser för familjemedlemmar ett år efter i jämförelse med ett år innan cancer diagnosen.

Totala kostnaden för anhörigas vårdkonsumtion ökade under året efter diagnos innefattande vårdkontakter inom öppen- och slutenvård, medicinska undersökningar av läkare, röntgenundersökningar och laboratorieprover ordinerade av läkare. Den totala kostnaden för anhörigas vårdkonsumtion inom hälso- och sjukvården ökade från 211 853 kronor ett år före diagnosen till 455 985 kronor ett år efter diagnos.

## Delstudie II

Syftet med studie II var att undersöka anhörigas hälsorelaterade livskvalitet (HRQoL) under ett år med start från 3 månader efter den närståendes diagnostillfälle. Det fanns inga signifikanta förändringar i fysiska eller i mentala dimensioner av HRQOL vid de fem mätillfällena. I jämförelse med en referenspopulation i SF-36 hade anhöriga statistiskt signifikant sämre HRQOL i mentala dimensioner med undantag för Rollfunktion - emotionella orsaker.

Signifikant sämre HRQOL framkom även i EQ-5D VAS för samtliga mätillfällen i jämförelse med referenspopulation. Anhöriga i åldern 20-65 hade statistiskt signifikant bättre värden i fysiska dimensioner vid samtliga fem mätillfällen i SF-36 i jämförelse med den äldre åldersgruppen 66-84.

Även partners hade sämre värden än vuxna barn på de fysiska dimensionerna. Partners hade statistiskt signifikant sämre HRQOL värden vid tre mätillfällen (9, 12 och 15-månader). De flesta partner i studien (56 %) var äldre (66-84 år) med sämre värden på de fysiska dimensionerna, som eventuellt kan förklaras av fysisk bräcklighet på grund av ålder.

## Delstudie III

Syftet med studie III var att undersöka vilka strategier anhöriga använder för att hantera sin situation i ett tidigt skede av behandlingen. Anhöriga hanterar den hotande framtiden genom att *sträva efter att vara förberedd för det smärtsamma* som kan komma. De *försöker göra det lättare i det dagliga livet och vill finnas till hands* för den sjuke så mycket de kan. De tar ledigt från arbetet eller ändrar arbetstider och planerar ändringar som underlättar vardagen. Vetskapen om att den cancersjuka personen inte kan bli botad från sin sjukdom och kommer att

avlida upplevs påfrestande och anhöriga *försöker förtränga tankar om framtiden*. De distanserar sig känslomässigt inför den hotande förlusten av den närstående och vill leva som vanligt för att orka stå ut med vardagen. *Att leva i nuet* blir betydelsefullt och de anhöriga kan inte planera vad de ska göra om en månad eller om ett år. I nuet kan de släppa de hotfulla tankarna om framtiden, för de är inte där ännu. De anhöriga vill tillbringa sin tid med den sjuke och *anpassar sig till den sjukas situation* och dagsform. Vardagen kretsar runt sjukdomen och de anhöriga vill finnas tillgängliga när som helst på dygnet. De upplever att familjen blivit allt viktigare och spenderar all tillgänglig tid tillsammans. Genom deras sociala nätverk kunde de *distrahera sig genom att vara tillsammans med andra* och skingra tankarna. I familjegemenskapen hämtar de kraft för att orka bära bördan som anhörig, både för sig själva och för att orka vara ett stöd för personen med cancer. De *försöker beskydda familjen från lidande genom* att bära de andra familjemedlemmarnas sorg på sina axlar, samt skyddar och skonar dem från känslomässiga påfrestningar. De har svårt att vara ärliga särskilt mot barnen och vill skydda och avlasta dem så att de inte blir ledsna. Behandlingen som den cancersjuka personen genomgår inger hopp hos de anhöriga. De vill på alla sätt stödja den cancerdrabbade i att hålla humöret uppe när negativa tankar kommer om den svåra diagnosen de har fått och *försöker hålla hoppet uppe*. Anhöriga försöker inrikta sig på de positiva med en förhoppning om en framtid tillsammans med den sjuka personen.

## Delstudie IV

Syftet med studie IV var att studera innebörden av socialt nätverk för anhöriga i ett tidigt skede av behandlingen, samt att validera resultaten med hjälp av Finfgeld-Connetts begreppsmodell [4] om socialt stöd. Anhöriga beskrev att de hade ett personligt *nätverk att vända sig till* när de kände att de behövde stöd. Det upplevdes som en trygghet att kunna vända sig till sitt nätverk och träffa sina vänner utan att behöva planera i förväg. Några önskade en *djupare relation med sina släktingar* och tyckte det var jobbigt att släktingar inte kunde hantera situationen och inte klarade av att upprätthålla kontakten. En del släktingar hade själva egna problem och orkade inte med att möta personen med cancer eller den anhöriges sorg.

Anhöriga upplevde *bekräftande samhörighet* av sitt sociala nätverk och stödet bekräftade dem i deras nya livssituation som anhöriga. De upplevde *förståelse och stöd från släktingar* genom att ha sina närmast i närheten som de kunde prata med, men de fick även praktisk hjälp i vardagen. Det var betydelsefullt för dem att ha *uppmuntrande grannar och vänner* som kom och hörde av sig vilket gjorde att de kände sig lugnare i situationen. Anhöriga uppskattade att *få information och personligt stöd av sjukvården* om olika frågor i samband med behandlingar som den cancersjuka personen genomgick. Det var viktigt att personalen informerade på ett sådant sätt att den anhöriga kände att personalen brydde sig och att information var riktad direkt till dem som anhöriga. De anhöriga upplevde *engagemang från arbetskamrater och arbetsgivare* som visade förståelse för deras situation och tog hänsyn till dem då de inte orkade prestera lika mycket som de annars vanligtvis orkade på arbetet. *Andlig tro i en stödjande gemenskap* upplevdes genom att delta i kyrkliga aktiviteter i sin församling och de regelbundna mötena gav anhörig tröst och avlastning. De anhöriga upplevde *störst förståelse från de personer som haft egna kriser*. Och förståelsen från dem som haft egna kriser gav dem kraft att orka vidare.

Jämförelse av resultatet i avhandlingen med begreppsmodellen visade att socialt stöd innebär ömsesidigt utbyte av verbal och icke-verbal information och socialt stöd ges främst av icke professionella vårdgivare. Jämförelsen visade att de flesta ord/begrepp i denna avhandling kunde återfinnas i Finfgeld-Connetts begreppsmodell (2005) om socialt stöd.

## Slutsatser och implikationer

Denna avhandling visar att anhöriga verkar ha ändamålsenliga hanteringsstrategier och hade mestadels stöd från sitt sociala nätverk i det tidiga stadiet av cancersjukdomen. Trots hanteringsstrategier framkommer att de som är informella vårdare utvecklar en risk för sjuklighet med ökad vårdkonsumtion och ökad muskuloskeletal och psykiatriska diagnoser året efter diagnosen. När familjemedlemmar är frånvarande från arbetet påverkas produktivetskostnaden negativt. De äldre anhöriga och partners hade en högre risk för sämre fysiska dimensioner av hälsorelaterad livskvalitet under året efter diagnos och yngre

familjemedlemmar hade en högre risk för sämre psykiska dimensioner av hälsorelaterad livskvalitet. Personerna som fick en cancer diagnos var allvarligt sjuka och hade en hög dödlighet, vilket visar att anhöriga lever under stark psykisk press. Därför behöver vårdpersonalen uppmärksamma varje anhörig som en egen individ utifrån dennes specifika behov och förutsättningar.

Evidensbaserat interventionsprogram som förebygger ohälsa och identifierar anhöriga som har ökad risk för ohälsa behöver utvecklas. Anhöriga bör erbjudas stöd i ett tidigt skede efter cancerdiagnosen för att minska deras psykiska och fysiska lidande. Om personal fokuserar mer på förebyggande strategier så kommer cancersjuka personer att få möjlighet till en förbättrad vård och anhöriga kommer att få förbättrad hälsa och ett minskat lidande. Stöd till informella vårdgivare kräver strategier i samarbete mellan olika sjukvårdshuvudmän, främst landstinget och kommunerna. Resultatet i denna avhandling visar anhörigas tidsinsatser och kostnader för samhället om personen med cancersjukdom inte hade haft stöd av sina anhöriga, vilket innebär att vården skulle ha utförts av professionella vårdgivare istället. Dessa identifierade kostnader, samt kostnader för anhörigas sjuklighet i termer av ökat antal läkarbesök och frånvaro från arbetet behöver studeras vidare. Allt fler personer lever med en cancersjukdom och kostnaderna för cancervården ökar. Fler longitudinella studier med ett större antal anhöriga behövs för att kunna verifiera anhörigas ökade risk för ohälsa som framkommit i denna studie.

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