

Families' life situation when living with cancer

Aspects of health and family sense of coherence

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**FAMILIES' LIFE SITUATION WHEN
LIVING WITH CANCER**

Aspects of health and family sense of coherence

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LINNAEUS UNIVERSITY PRESS

Families' life situation when living with cancer: Aspects of health and family sense of coherence

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Abstract

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Aim: To investigate families' perceived life situation when living with cancer, with a focus on health and family sense of coherence.

Methods: Study I is a population-based register study that explored how cancer influenced the health of cohabitating partners of persons with cancer in Sweden by examining the onset of new diagnoses, health care use, and health care costs among the partners. Study II focused on familial interaction patterns for families living with cancer in a palliative phase, based on family interviews, and analysed using Gadamerian hermeneutics. In study III, Family Sense of Coherence scale (S-FSOC-S) was culturally adapted and evaluated for reliability and validity, using psychometric analyses. Study IV explored associations between family sense of coherence and hope, anxiety, and symptoms of depression using descriptive statistics and nested linear regression.

Results: Study I showed that the partners of persons with cancer had significantly increased health care use and health care costs both one and two years after the cancer diagnosis, and that use patterns and costs varied according to the type of cancer that had been diagnosed. Study II revealed that the familial interaction patterns were adjusted in response to changes in family life - changes which encompassed three different, but interrelated, patterns: *power dynamics in the family*, *the "secret game" in the family*, and *multifaceted closeness and distance in the family*. Study III suggested that S-FSOC-S is useful for assessing familial coherence and shows satisfactory reliability and validity. Study IV showed that stronger family sense of coherence was associated with higher hope and lower anxiety and symptoms of depression levels in both persons with cancer and their family members.

Conclusions: Families' life situation was affected by the cancer diagnosis, which had an impact on both individual family members and the family as a unit. The type of cancer may help to determine partners' risk of ill health. The changed familial interaction patterns increased the families' ability to deal with family life without hurting each other. The S-FSOC-S is a useful instrument for assessing family sense of coherence and can help identify families with weak family sense of coherence, who may need professional support.

Keywords: Cancer, Family interviews, Family sense of coherence, Health, Palliative care, Psychometric evaluation

ABBREVIATIONS AND DEFINITIONS	4
ORIGINAL PAPERS	5
PREFACE	6
INTRODUCTION	7
BACKGROUND	9
LIVING WITH CANCER	9
<i>An individualistic perspective.....</i>	<i>10</i>
Persons living with cancer	10
Family members	11
<i>A family perspective.....</i>	<i>12</i>
FAMILY-FOCUSED CARE.....	13
SIGNIFICANT CONCEPTS	14
<i>Health</i>	<i>14</i>
<i>Family sense of coherence</i>	<i>15</i>
RATIONALE FOR THIS THESIS	17
AIMS	18
OVERALL AIM.....	18
SPECIFIC AIMS	18
METHODS.....	19
SETTINGS	19
STUDY I	20
<i>Participants.....</i>	<i>20</i>
<i>Data collection.....</i>	<i>21</i>
<i>Data analysis</i>	<i>21</i>
STUDY II	21
<i>Participants.....</i>	<i>21</i>
<i>Data collection.....</i>	<i>22</i>
<i>Data analysis</i>	<i>23</i>
STUDY III	24
<i>The S-FSOC-S scale.....</i>	<i>24</i>
<i>Translation and cross-cultural adaptation</i>	<i>24</i>
<i>Examination of content validity.....</i>	<i>25</i>
Cognitive interviews	25
Content validity index.....	26
Revisions of S-FSOC-S after examination of content validity	26
<i>Psychometric evaluation.....</i>	<i>28</i>

Participants.....	28
Data collection.....	29
Herth Hope Index (HHI-S).....	29
Hospital Anxiety and Depression Scale (HADS).....	29
Data analysis.....	29
STUDY IV.....	30
<i>Participants and data collection</i>	30
<i>Data analysis</i>	30
ETHICAL CONSIDERATIONS.....	31
RESULTS	32
THE PARTNER'S HEALTH (I).....	32
<i>Increased diagnoses for partners after the cancer diagnosis</i>	32
<i>Increased health care use and health care costs for partners after the cancer diagnosis</i>	32
FAMILIAL INTERACTION PATTERNS DURING THE PALLIATIVE PHASE (II).....	33
<i>Power dynamics in the family</i>	33
<i>The 'secret game' in the family</i>	34
<i>Multifaceted closeness and distance in the family</i>	34
EVALUATION OF THE SHORT VERSION OF THE FAMILY SENSE OF COHERENCE SCALE AMONG PERSONS WITH CANCER IN THE PALLIATIVE PHASE AND THEIR FAMILY MEMBERS (III).....	35
ASSOCIATIONS OF FAMILY SENSE OF COHERENCE WITH HOPE, ANXIETY, AND SYMPTOMS OF DEPRESSION RESPECTIVELY (IV).....	37
DISCUSSION	38
<i>Consequences for families when living with cancer</i>	38
<i>Consequences for partners when living with the person with cancer</i>	39
<i>Consequences for health care</i>	41
<i>Family sense of coherence</i>	41
METHODOLOGICAL CONSIDERATIONS.....	42
<i>Trustworthiness (II, III)</i>	43
<i>Validity and reliability (I, III, IV)</i>	45
CONCLUSIONS	48
CLINICAL IMPLICATIONS.....	48
FUTURE RESEARCH.....	49
SVENSK SAMMANFATTNING	50
BAKGRUND.....	50
SYFTE.....	51

METOD	51
RESULTAT	51
SLUTSATSER OCH KLINISKA IMPLIKATIONER.....	53
FÖRSLAG PÅ FORTSATT FORSKNING	54
ACKNOWLEDGEMENTS.....	55
REFERENCES	57

Abbreviations and definitions

ICD 10	International Statistical Classification of Diseases and Related Health Problems
FSOC	Family Sense of Coherence Scale, 26 item
FSOC-S	Family Sense of Coherence Scale, 12 item
S-FSOC-S	Swedish Family Sense of Coherence Scale, 12 item
PCA	Partners of persons with cancer
PCO	Partners of controls without cancer
WHO	World Health Organization

Family - An individual's *family* is defined by that individual, and includes anyone whom they think is a part of their family (at least one other person). This leaves open-ended the number of different potential family structures (since they can also include significant persons such as friends). In short, the family is who they say they are (Wright & Leahey, 2013).

Health - The WHO define *health* as a “*complete state of physical, mental, and social well-being and not necessarily only absence of disease or infirmity*” (WHO, 1948).

Interaction - Interaction encompasses the dynamic and constantly changing process of communication and relationships between people (Freidman, Bowden, & Jones, 2003).

Palliative care - The definition of *palliative care* from the WHO (2015) runs as follows:

“An approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves of suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual”

Palliative phase - The palliative phase of the cancer starts when the cancer becomes incurable (Socialstyrelsen, 2017).

Partner – A person's *partner* is defined by a relationship with that person characterized by trust, empathy, closeness, commitment, love, and satisfaction (Reis & Collins, 2000). In this thesis, partners are also limited to those living together at the same address as the person with cancer and not including parents, siblings or children.

Original Papers

This thesis is based on four original papers that will be referred to in the text by their Roman numerals, I - IV.

- I. Möllerberg, M-L., Sandgren, A., Lithman, T., Noreen, D., Olsson, H. & Sjövall, K. (2016) The effects of a cancer diagnosis on the health of a patient's partner: a population-based registry study of cancer in Sweden. *European Journal of Cancer Care*. Sep, Vol.25 Issue 5, 744-752.
- II. Möllerberg, M-L., Sandgren, A., Swahnberg, K. & Benzein, E. (2017) Familial interaction patterns during the palliative phase of a family member living with cancer. *Journal of Hospice and Palliative Nursing*. Feb, Vol.19 Issue 1, 67-74.
- III. Möllerberg, M-L., Årestedt, K., Sandgren, A., Benzein, E. & Swahnberg, K. Adaptation and psychometric evaluation of the short version of the Family Sense of Coherence Scale in a sample of persons with cancer in a palliative phase and their family members: An evaluation study. *Cancer Nursing*. Submitted.
- IV. Möllerberg, M-L., Årestedt, K., Swahnberg, K., Benzein, E. & Sandgren, A. Family sense of coherence and its associations with hope, anxiety and symptoms of depression in persons with cancer in a palliative phase and their family members: A cross-sectional study. Manuscript.

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Preface

My interest in cancer care research developed from my experience in clinical nursing, where I have met families during different stages of the cancer trajectory. During my 27 years of clinical work as a nurse I met these families in various contexts, including surgical, medical, cancer, and palliative care. While working as a nurse in palliative home care, I considered the patient's family members to be a natural part of their care; however, cancer and palliative care continue to a great extent to have an individualistic focus, even though family members can be a part of the caring process. My professional experience has raised my awareness of and increased my interest in care for persons with cancer and their family members. Therefore, the starting point of my research was how families managed their new life situation when one family member was diagnosed with cancer.

Introduction

Today, in Sweden, it is estimated that at least every third person will receive a cancer diagnosis during their lifetime. Incidence of cancer is increasing every year and 61 100 persons were diagnosed with cancer in 2015 (Cancerfonden, 2017). Moreover, cancer is the second-most-common cause of death in Sweden (Socialstyrelsen, 2013). With increases in cancer incidence, improvements in treatment methods, and a growing number of people surviving, more people are living a prolonged time with cancer (Socialstyrelsen, 2012) not only in Sweden, but also in the rest of Europe (Ferlay et al., 2013). Being diagnosed with cancer puts people at a crossroads; on the one hand, the cancer may be cured and the person survive, or, on the other hand, the cancer may be incurable and the person may live with the cancer for a shorter or longer period, but still reach death earlier than they otherwise would have. The palliative phase begins when the cancer is determined to be incurable; however, clinically, it is not always possible to know at the diagnosis of the cancer whether it is curable or not (Hansson, Henriksson, & Peterson, 2008).

It is evident that the new life situation that follows a cancer diagnosis in a family influences the whole family; however, it may influence each individual in different ways (Andersson et al., 2010; Missel & Birkelund, 2011; Northouse, 2012). As cancer is a life-threatening disease, all family members of persons with cancer will likely think of their own death and of the death of their loved one (Carlander et al., 2011); subsequently, all family members' health, including that of the ill person, may be affected by the range of emotions that may occur in both the person diagnosed with cancer and in his/her family members (Andersson et al., 2010; Blanchard, Albrecht, & Ruckdeschel, 1997; Pusa, Persson, & Sundin, 2012). Family members have an important role in providing support to persons with cancer. Nevertheless, having a person with cancer in one's family may increase the risk to both mental (Goren et al., 2014; Sjøvall et al., 2009) and physical ill health (Sjøvall et al., 2009; Stenberg, Ruland, & Miaskowski, 2010), especially when the person with cancer is one's partner. This may negatively influence the family functioning and interaction, that is, the constantly changing process of communication and interpersonal relationships within the family (Freidman et al., 2003). Experience of ill health in the family is especially elevated when the patient's physical symptoms worsen and when they come to be in need of palliative care (Given, Given, &

Sherwood, 2012; Grunfeld et al., 2004; Heins et al., 2013; Nakaya et al., 2010; Rhee et al., 2008); this is associated with reduced quality of life (Clark et al., 2010; Gao et al., 2010; Hagedoorn et al., 2008; Zabora et al., 2001).

Many families are capable of managing such as situation appropriately by themselves, but other families need help and support. A health promotive model such as Antonovsky's salutogenic model, in which sense of coherence is the core concept, has been shown to be a concept that promote family functioning and well-being (Lustig & Akey, 1999; Ngai & Ngu, 2011), predict quality of family life (Andersson, 1998; Hsiao, Lu, & Tsai, 2017) and predict the occurrence of psychological distress (Ngai & Ngu, 2014) in various contexts outside palliative care. Whether this is also true in palliative care should be investigated. Also, there is a need to identify the families in most need of care and of professional supportive interventions, and doing so requires validated instruments measuring relevant variables, for example, family sense of coherence. Therefore, this thesis deals with the life conditions of families living with cancer, with a focus on health and family sense of coherence.

Background

This background chapter starts with an overview of the relevant scientific literature, including that on living with cancer from an individualistic and from a family perspective (excluding research on families of children with cancer). Then follow brief descriptions of family-focused care and of two significant concepts: health and family sense of coherence.

Living with cancer

Individual family members and the family as a whole encounter diverse challenges when one family member is diagnosed with cancer, and these challenges may increase when the cancer moves into the palliative phase. Cancer, like many other illnesses, can be considered a ‘family illness’, because it influences the entire family in one way or another (Missel & Birkelund, 2011; Northouse, 2012). All family members have to adapt emotionally and physically to their new life situation both when the cancer is curable (Flanagan & Holmes, 2000; Hagedoorn et al., 2008) and when it is palliative (Carlander et al., 2011; Fjose et al., 2016; Flanagan & Holmes, 2000; Missel & Birkelund, 2011; Pusa et al., 2012). When living with cancer in a palliative phase, persons with cancer and their family members are faced with constant waiting and often feel that their lives are being put on hold (Sandgren et al., 2010). Additionally, a cancer diagnosis disrupts the life situation of all involved persons both when the cancer is curable and when it is palliative, introducing or exacerbating issues such as uncertainty, fear, and intrusive thoughts about mortality, treatment, disabilities and survival (Venetis, 2014). In both the curable and palliative phases the research regarding the family’s situation when one family member is living with cancer has primarily been conducted from an individualistic perspective, including either the person with cancer or a family member, and there is a limited amount of research with a family-focused orientation. Also, the majority of research has involved the most common cancer types (prostate, breast, lung, colon, and rectal cancer).

An individualistic perspective

Persons living with cancer

Regardless whether the cancer is curable or in a palliative phase, close relationships and social support can be important factors in adaptation and achievement of well-being when one has been diagnosed with cancer, which can substantially affect one's quality of life (Emslie et al., 2009; Flanagan & Holmes, 2000). At the same time, however, the existence of those relationships and social support may also be experienced as a stressor for a person with cancer who feels responsible for his/her family's wellbeing, and in that sense, may generate negative effects on that person's quality of life as well (Corner et al., 2007; Flanagan & Holmes, 2000). According to persons with curable cancer, maintaining normality can be helpful when adapting to the new life situation; however, they still had concerns that their cancer might change the way their family members behave (Richardson, Morton, & Broadbent, 2015). Moreover, there are times when persons with curable cancer choose not to talk about the disease, and in these cases, they sometimes wish to receive encouragement from family members to speak openly about their feelings and experiences (ibid). These situations may also occur when the cancer is incurable (James, Andershed, & Ternstedt, 2007). Other common symptoms during the cancer trajectory are experiences of psychological distress, such as anxiety and depression (Clark et al., 2010; Zabora et al., 2001), which are associated with reduced well-being and therefore a risk of ill health (Hagedoorn et al., 2008). Furthermore, anxiety and depression are associated with increased health care utilization, hopelessness, decreased well-being and poor social functioning for persons with incurable cancer (Arrieta et al., 2013; Jaiswal, Alici, & Breitbart, 2014).

Anxiety and depression may also have negative effects on psychological adjustment and overall quality of life (Somerset et al., 2004) as well as survival rates (Brown et al., 2003; Jacobsen, 2007; Somerset et al., 2004) for persons with curable cancer. Some persons with curable cancer believe they have enough resources within their social network to manage their life situation, while others have a need for additional professional health care support (Richardson et al., 2015), especially to improve their understanding of their condition and develop strategies to handle daily life (ibid). Moreover, when the cancer has passed to a palliative phase, the person with cancer may fear both being a burden to their family and being abandoned, which may contribute to

their effort to maintain independence as long as possible (Eriksson & Andershed, 2008). In addition, persons with cancer in a palliative phase require hope to maintain their dignity and to enhance their quality of life (Alidina & Tettero, 2010). Nevertheless, it is common to experience decreased hope (Marchand, 2015) and sometimes they need to create a new meaning (Laranjeira, Leao, & Leal, 2013) in their life during the palliative phase.

Family members

The closest relative of the person with cancer is often his or her partner, who has an important role in providing support to the person with cancer, whether it is curable or incurable (Emslie et al., 2009; Sjøvall et al., 2009). Living as a partner of a person with colorectal cancer have been described as living in the shadow of the disease (Sjøvall et al., 2011). Indeed, the psychological burden is in some cases greater for partners than for persons with either curable (Hagedoorn et al., 2008) or incurable (Braun et al., 2007; Lichtenthal et al., 2003; Northouse et al., 2005) cancer. Partners may experience symptoms like sleep problems and eating disorders (Stenberg et al., 2010) and are also at increased risk for experienced depression (Drabe et al., 2008; Hagedoorn et al., 2000; Nakaya et al., 2010) and anxiety (Maguire & Pitceathly, 2003), both when the cancer is curable and when it is in a palliative phase. Additionally, an increased risk of psychiatric diagnoses is seen in partners of persons with colon, lung, and prostate cancer, as compared with the risk prior to the cancer diagnosis (Sjøvall et al., 2009). Furthermore, partners of persons with lung cancer have an increased health care use and costs during the first year after the cancer diagnosis (Jassem et al., 2015; Sjolander et al., 2012; Sjøvall et al., 2009). Partners and other family members also have an increased risk of poor physical and mental health (Goren et al., 2014; Sjolander et al., 2012; Sjøvall et al., 2009), which escalates when the patient's physical symptoms worsen (Given et al., 2012; Heins et al., 2013). Decreased hope (Hasson-Ohayon et al., 2014) and difficulties finding meaning or creating new meaning in life (Totman et al., 2015) are common symptoms for family members during the cancer trajectory, and hope is important for family members' ability to cope and manage their life situation (Hasson-Ohayon et al., 2014). Ways family members can create new meaning in their lives could including providing support (e.g., time, emotional support) to the person with cancer in a palliative phase or acceptance and gratitude for the time they have and have had together (Totman et al., 2015). Moreover, there seems to be connections of both the type of cancer (breast, prostate, lung, colon and rectal) and the disease stage with partners' health

(Sjovall et al., 2009). This may have psychosocial consequences such as missing work (Grunfeld et al., 2004). Family members living close to a person with cancer may also often focus primarily or disproportionately on that person's needs (Missel & Birkelund, 2011) and it may be confusing how to behave when a family member has cancer in a palliative phase (Sandgren, 2012). Family members may play an important role in providing emotional and practical support to the person with cancer (Maly et al., 2005) and may also take on the role of care provider for their loved one, especially when palliative care is needed (Hartnett, Thom, & Kline, 2016). If a family member takes on this role of providing care, it may have a negative impact on their own personal time, social roles, physical and emotional state, and financial resources (Given, Given, & Kozachik, 2001).

A family perspective

Below follows an overview of the scientific literature on living with cancer from a family perspective.

Cancer in a palliative phase influences daily life for the entire family in one way or another (Carlander et al., 2011; Fjose et al., 2016). Persons with cancer and their family members have an interdependent relationship whereby each family member affects the others, both when the cancer is curable and when it is incurable (Hagedoorn et al., 2008; Northouse, 2012). Similarly, studies have suggested that psychological distress in persons with cancer and their family members may be interdependent when the cancer is curable (Hagedoorn et al., 2008; Rottmann et al., 2015) and when it is incurable (Kershaw et al., 2015). Additionally, living as a couple with cancer may either bring partners closer together or create emotional distance between them (Traa, De Vries, Bodenmann, & Den Oudsten, 2015). When the cancer passes on to a palliative phase, open communication facilitates family coping (McLeod et al., 2010), but couples may struggle with how to communicate and adjust to new responsibilities and roles in order to achieve optimal functioning in the relationship (Traa et al., 2015). Furthermore, both curable cancer and cancer in a palliative phase have impacts and consequences far beyond the immediate family in terms of making the situation comprehensible, manageable, and meaningful and achieving balance in the family (Illingworth et al., 2010). This is seen in the way families strive to find out how each family member can contribute to finding an optimal way to manage family life in the palliative phase (Carlander et al., 2011). The interdependent relationship within couples

living with cancer indicates the need to treat the couples as a unit of care (Northouse, 2012).

Family-focused care

In family-focused care, there is an assumption that the ill person is influenced by the people around them as well as by their general environment (Freidman et al., 2003). This has implications for both individual family members and the family as a unit, and adds valuable information about individuals and the family unit that can be applied to help alleviate suffering and support the process of achieving well-being to the degree possible (Bell, 2013). *Family-related care* and *family-centred care* are the two views that exist within the family-focused care approach in Sweden (Benzein, Hagberg, & Saveman, 2017), where family-related care focuses on individual family members (persons with illness or other family members), while the rest of the family is regarded as the context (Benzein et al., 2017; Ganong, 2011; Wright & Leahey, 2013). Family-centred care focuses on the family as a unit from the perspectives of several family members simultaneously (ibid). Family-centred care, also referred to as Family Systems Nursing, regards the family as a system in which elements mutually impact each other and their interactions, relationships, and reciprocity are of great significance (Benzein et al., 2017). A family system is composed of many subsystems, which in turn are composed of subsystems of individuals (Wright & Leahey, 2013).

With a family focus the aim is to maintain all family systems with a goal of family health and well-being while directing practice toward both health promotion and relief from suffering due to illness for the person with cancer (Bell, 2009). In particular, a family focus allows observations of the interactions among the family and between the family and the illness (Wright & Leahey, 2013), encompassing the constantly changing processes of communication and relationships between people involved (Freidman et al., 2003). Family members' interactions are best understood by taking a circular view of causality, since there is no prescribed beginning or end (ibid). Based on this view, a family's experiences are then more than the sum of each family member's experiences (Wright & Leahey, 2013). Furthermore, focus on the family make it possible to identify the unique strengths and resources of each particular family and individual family members to deal with challenges and support the

recovery process (Bell, 2013), in both healthy contexts and contexts of illness (Freidman et al., 2003).

It is not enough to only examine one part of the system to get full knowledge of the whole system and its process (Lundsbye, 2010). The reality can be understood as multidimensional, which means that individuals' different descriptions of the same situation are equally accurate (Bateson, 1998). Each family member and family has its own unique structure and functioning (Wright & Leahey, 2013). Within a family focused care, the family itself decides its structure and members (Whall, 1986), or as Wright and Leahey (2013) says (on page 60) 'Family is who they say they are'. This means that the individual defines who they think is a part of their own family, opening up an unlimited number of potential structures of the family (which can also include significant persons such as friends). A self-defined family can also mean that traditionally included family members can be excluded, perhaps due to disagreements or lack of trust related to earlier conflicts (Benzein et al., 2017). The members of a family may change over time, and some new members may be included and others excluded (Kirkevold & Strömsnes Ekern, 2003).

Significant concepts

This thesis focuses on two significant concepts; health and family sense of coherence. Below follows a very short description of health related to the definition by WHO (1948) and Antonovsky's model of salutogenic health (Antonovsky, 1987).

Health

Health and disease are not necessary opposites, a person can experience health and live with a diagnosed disease simultaneously. The opposite is also possible, to experience ill health without a diagnosed disease. Health is well known to be a multi-dimensional concept that varies depending on sample and context (Poortaghi et al., 2015). The WHO definition of health includes physical, mental, and social well-being (WHO, 1948), and applies to both individuals and families (Rowe-Kaakinen, Steele, & Padgett-Coehlo, 2014). It also spells out that health is not only absence of disease or infirmity (WHO, 1948) but encompasses of different aspects of well-being, which may have contributed to the confusion between health and well-being that sometimes exists among researchers. Well-being could be defined in terms of basic needs and the degree

to which they are met or as a satisfactory condition of existence (Thorne, Griffin, & Adlersberg, 1986). The salutogenic perspective takes the WHO's definition and expands it to also include quality of life (Eriksson, 2015). For individuals living with cancer in the family health could be described in terms of events that can markedly alter the quality and quantity of life (Dulaney et al., 2017). According to Antonovsky (1987) health and disease are viewed as a relative continuum along which each person at each given point of time can be somewhere along this health ease – dis-ease continuum. An individual's health affects his or her entire family's interactions, and in turn, the family's ability to interact affects each individual member's health. The stress of a family member's illness influences family functioning and health and that of the individual members, as do (collective and individual) familial behaviours, actions, or reactions to illness (Anderson & Tomlinson, 1992). To experience health, people need to understand their own lives and be understood by others, perceive themselves as able to manage their live situations, including serious family illness, and perceive life as meaningful enough to find the motivation to continue (Antonovsky, 1987).

Family sense of coherence

According to Antonovsky, an important factor in health is sense of coherence (Antonovsky, 1987). His salutogenic model, in which sense of coherence is a core concept, focuses on health resources instead of disease risks: salutogenesis is a way of thinking, acting, and interacting with people in a manner that promotes health promotion (Eriksson, 2007). Sense of coherence is applicable at both an individual and group (family) level (Sagy, 1998). Antonovsky developed family sense of coherence to explain why families do not experience diminished health when they meet stressors which they need to cope with to make sense of difficult situations. Family sense of coherence may describe health-protective behaviour patterns that have a stress buffering effect (Antonovsky, 1987). The resources the family uses depend on the characteristics of family members and their ways of facilitating stress management (Antonovsky, 1987; Eriksson, 2007). Family sense of coherence consists of three interrelated factors; *comprehensibility*, *manageability* and *meaningfulness*. Comprehensibility describes whether or not the family finds that internal and external stimuli are coherent and structured, whether they have the ability to understand the situation clearly. Manageability describes whether the family have the belief that they have access to sufficient internal and external resources to handle the challenges of the situation. Meaningfulness describes

areas in life that are important for the family and whether given challenges are worth the energy investment (Antonovsky, 1987).

There have also been efforts to operationalize the concept family sense of coherence. Two questionnaires are developed; one with 26 items (FSOC) (Antonovsky & Sourani, 1988) and one with 12 items (FSOC-S) (Sagy, 1998). The questionnaires are sought to be answered individually, but can be analysed at a family level. None of these questionnaires were available in Swedish at the onset of this thesis.

Rationale for this thesis

Since cancer incidence is increasing and since treatments and survivorship are lasting for a longer period of time, families are more likely to live with cancer and encounter negative consequences of it. The impact is on both individual family members and the family as a unit; these risks also increase the challenges for health care providers caring for these families. However, only a limited number of studies address a family focus when living with cancer, whether it is curable or in a palliative phase. Further, most of the research has covered only the five most common cancer types. Therefore, there is a need to investigate differences and similarities among family members of persons with cancer across cancer types. There is also a need to identify families who have a need for professional support, which can be done using self-rating questionnaires. Therefore, a validated screening questionnaire with a family focus is warranted. In family-focused care, it is crucial to understand both the parts (individuals) and the whole (the family as a unit) to gain sufficient knowledge about the families' life circumstances. Therefore, both family-related and family-centred studies are needed to increase knowledge about these families' challenges and how they influence family members' health and their ability to understand and manage their situation in a meaningful way. Increased knowledge about the impact on families' health, interactions, and sense of coherence can contribute to increased well-being for individual family members and the family as a unit, both in short- and long-term perspective. Through this knowledge, the health care can develop caring strategies to identify families' needs and who are in need of professional support and thereby be able to develop suitable interventions covering the families' needs.

Aims

Overall aim

The overall aim of this thesis was to investigate families' perceived life situation when living with cancer, with a focus on health and family sense of coherence.

Specific aims

Study I: To explore how cancer influences the health of partners, by examining the onset of new diagnoses for partners, health care use and health care costs among partners living with patients with cancer.

Study II: To illuminate aspects of familial interactions when one member is in the palliative phase of his/her cancer course.

Study III: To translate, culturally adapt, and validate the short version of the Family Sense of Coherence Scale in a Swedish sample of families living with cancer in the palliative phase.

Study IV: To determine whether family sense of coherence was associated with hope, anxiety and symptoms of depression respectively in persons with cancer in the palliative phase and their family members.

Methods

Studies with a family focus may target individual family members, individuals on a group level, or the family as a unit (Wright & Leahey, 2013). These three perspectives were used to capture family life situations from multiple angles. A complementary combination of quantitative (I, III, IV) and qualitative (II, III) methods was used, as well as multiple designs: longitudinal (I), exploratory (I, II, IV), evaluative (III), and cross-sectional (IV) designs. Applied designs and methods were guided by the different aims and research questions of the different studies (Polit & Beck, 2012) to get a deeper understanding of the family's life situation when living with cancer (Table 1).

Table 1. Overview of the specific studies.

Study	Design	Participants	Data collection	Analysis
I	Quantitative, exploratory, longitudinal	Partners of persons with cancer (N=10 353), control group (N=74 592)	Population-based register data	Logistic regression analyses, descriptive statistics
II	Qualitative, exploratory	13 families (n=29) where one family member is living with cancer in palliative phase	Family interviews	Hermeneutic analysis
III	Psychometric, evaluative	Persons with cancer (n=9) and family member (n=1) (cognitive interviews) Experts (n=7) (CVI) Persons with cancer (n=179) and family members (n=165) (psychometric evaluation)	Cognitive interview, content validity index (CVI), self-reported questionnaires (HADS, HHI-S, S-FSOC-S)	Descriptive statistics, item analysis
IV	Quantitative, exploratory, cross-sectional	179 persons with cancer and 165 family members (same sample as in study III, psychometric evaluation)	Self-reported questionnaires (HADS, HHI-S, S-FSOC-S)	Linear regression analyses, descriptive statistics

Settings

The research in this thesis was conducted in three counties, in southern Sweden. The largest county has nine hospitals and 1.3 million inhabitants, the middle-sized county has three hospitals and 242 000 inhabitants and the smallest county has two hospitals and 196 000 inhabitants (all figures from 2016). The first

study was a population-based register study which included all care, both inpatient and outpatient, in the largest county. In the following three studies (II–IV), the participating families were recruited from two oncology clinics and two palliative centres across all three counties. The oncology clinics included day-care units from two hospitals in the largest county and a palliative consulting team in the smallest county, while the palliative centres consisted of palliative home care and hospice wards in the middle and largest counties.

Study I

This study is part of a survey designed to map and analyze cancer in the Southern Health Care Region of Sweden (Attner et al., 2008). The design was adapted from that used in an earlier study (Sjovall et al., 2009). As a result of these characteristics, study I includes all types of cancer and detailed diagnoses codes of the partners.

Participants

The study cohort consisted of partners (N=10 353) of all persons who received a cancer diagnosis during 2005-2007 in the largest county in southern Sweden. Controls (age- and sex-matched to the persons diagnosed with cancer) were selected, and their partners (N=74 592) were included as a comparison group. A ‘partner’ was defined as the adult (> 15 years old) who lived at the same address as the ill person (or the matched control person) at the date of the cancer diagnosis. The characteristics of partners are shown in Table 2.

Table 2. Characteristics of included partners of persons with cancer (PCA) and partners of controls with no cancer (PCO).

	PCA	PCO
N	10 353	74 592
Sex, n (%)		
Male	3 934 (38.0)	29 091 (39.0)
Female	6 419 (62.0)	45 501 (61.0)
Age groups, n (%)		
< 65 years	4 866 (47.0)	38 042 (51.0)
> 65 years	5 487 (53.0)	36 550 (49.0)

Data collection

This study used the population-based Cancer Registry of Southern Sweden, the Census Registry of Sweden, and the Health Care Registries of Southern Sweden to receive data, identified by unique Swedish 10-digit personal identification number. All persons diagnosed with cancer, during the years 2005-2007, were first identified in the Cancer Registry of Southern Sweden. The cancer diagnoses were classified into 18 major types and one category of miscellaneous cancers, which included unknown cancer, head and neck cancer, and other rare cancer diagnoses. Partners of persons with cancer (PCA) and partners of controls with no cancer (PCO) were identified via the Census Registry of Sweden. Data from Health Care registries of Southern Sweden were used for their diagnoses, health care use, and health care costs. All health care data were measured over a continuous period that began one year before the date of cancer diagnosis and continued for three years. The partner's age was also assessed, at the time of cancer diagnosis.

Data analysis

Conditional logistic regression was used to analyse health care use and determine which diagnoses were most affected in PCAs, using risk ratios (RRs) with 95% confidence intervals (CIs). The regression model was stratified by age and sex. RRs were also used to identify changes over time and to compare health care costs for PCAs and PCOs. Diagnoses, health care use, and health care costs were compared between one year before the cancer diagnosis and one and two years after the cancer diagnosis. Health care use data in the PCA group included number of inpatient and outpatient contacts. For both the PCA and PCO groups, total health care costs were assessed based on the individuals' diagnoses related groups, as well as the number of outpatient contacts and inpatient care episodes. Health care costs were listed for each individual partner, aggregated for the PCA and PCO groups, and compared between the groups.

Study II

Participants

Families were recruited using purposive sampling between May 2014 and June 2015. Inclusion criteria were families with an adult member diagnosed with cancer in a palliative phase and with a minimum of one additional family member who could participate in the interview. Participants were recruited based on verbal and written information given by nurses at the clinic. Those

who were interested in participating sent their telephone number in a pre-stamped envelope to the researcher, who then called potential participants to answer questions regarding the study; interviews were subsequently scheduled with those who agreed to participate. The persons with cancer decided which family member they would like to bring to the interview. The study included 13 families, and the majority of the persons with cancer chose to invite one family member (11 interviews), while the other two invited two and three family members, respectively. The characteristics of the families are shown in Table 3.

Table 3. Characteristics of included families.

	Persons with cancer	Family members
Sex, n		
Male	5	8
Female	8	8
Age (years), mean (SD) [Range]	66.4 (7.6) [46-74]	61.3 (13.7) [37-77]
Marital status, n		
Married/ cohabiting	12	14
Single	1	2
Years since diagnosis, mean (SD) [Range]	5.6 (3.2) [2-12]	

Data collection

Eleven interviews were conducted in the participant's home, one at the local university, and one at a hospital. Interviews were conducted with multiple family members together to facilitate interaction, and thereby gain another perspective on how the family interacted and communicated with each other (Beitin, 2008; Eggenberger & Nelms, 2007). An interview guide was developed, for this study, including examples of questions about the past and present life situation of the families. Initial questions included 'Can you tell me about your family situation before the cancer diagnosis?' and 'Can you tell me about your family situation after the cancer diagnosis?' Clarifying questions were also asked, for example, 'Can you tell me more about that?' Other questions, such as, 'What are your thoughts about what your partner just said?' were asked as well in order to gain more information on the interactions within the family system. Before the data collection phase began, the interviewer wrote down her own thoughts and beliefs about the topic to clarify her pre-understanding; the same was done before each interview by writing field notes

to record her thoughts and perceptions; these were accompanied after each interview by field notes including observations about the interactions and conversations. All interviews were conducted by the author of this thesis, lasted between 42 and 90 min, and were recorded as mp3 files.

Data analysis

Data consisted of field notes and verbatim transcribed interviews subjected to a Gadamer-inspired hermeneutic analysis (Austgard, 2012; Fleming, Gaidys, & Robb, 2003), based on Gadamer's conception of understanding (Gadamer, 2004) as formed through a dialectic process of questions and answers and interpretation based on existing prejudices. In a hermeneutic inquiry, throughout the interpretation process the researcher goes back and forth between the parts and the whole (the 'hermeneutical circle'), with the aim of gleaning new understandings and meanings (Fleming et al., 2003; Ödman., 2007). The initial prejudice will then change based on this activity throughout the course of data collection and interpretation (Austgard, 2012). These features make Gadamerian analysis a suitable method to explore phenomena related to human experiences, as it offers possibilities of reinvention of understandings and meanings and new ways of viewing human experiences (McCaffrey, Raffin-Bouchal, & Moules, 2012).

During the analysis process, the researcher focused on interactions, individual family members, and the whole family unit, for all 13 families. The transcripts and field notes were read several times to get a sense of the whole and to search for the essential meaning(s) of the data. It was important to identify the research group's prejudice of the topic in order to move forward with the analyses (Austgard, 2012). Throughout the process of analysis, the researcher challenged all interpretation by questioning: could it be otherwise? Thereafter, each interview was reread to confirm the identified experiences and patterns and gain additional understanding; then, similar patterns were clustered together and an overall pattern revealed. Then, to search for meaning(s) of the pattern(s) and explore the families' experiences more deeply, the interviews were re-examined with the identified pattern(s) in mind: with a focus on the family's interactions, the analysis was reviewed, discussed, and refined by the research group to ensure credibility. Throughout the analysis, every attempt was made to keep an open mind. Ultimately, the interpretations reached a point where some patterns could be identified; thereafter, similar experiences were clustered together, achieving a deeper understanding (Austgard, 2012).

Study III

This psychometric study of S-FSOC-S was conducted in three steps: 1) translation and cross-cultural adaptation, 2) examination of content validity, and 3) psychometric evaluation.

The S-FSOC-S scale

To measure the perceived coherence of family life, a long version of the FSOC scale, with 26 items, was developed by Antonovsky and Sourani (1988). In this thesis, a shorter version, with 12 items (S-FSOC-S), was used, originally developed by Sagy (1998). The S-FSOC-S scale is rated on a numerical rating scale ranging from 1 to 7. There is a statement at the extremes, i.e. 1 and 7, sometimes different for each item. The following is an example of an item: *‘To what extent do you have the feeling that you can influence what happens in your family?’* A score of 1 stands for ‘not at all’ and score of 7 stands for ‘to a great extent’. The scale is answered individually and all responses are then aggregated to a total score which ranges from 12–84; a higher score indicates a higher level of perceived family sense of coherence. In palliative care, family sense of coherence has not been very well studied; however, in other research areas, family sense of coherence seems to predict quality of family life for families living with schizophrenia (Hsiao et al., 2017) or chronic illness (Andersson, 1998) and to correlate with lower psychological distress in childbearing couples (Ngai & Ngu, 2013, 2014). Permission for the translation and use of the short version of the S-FSOC-S was granted by Dr S. Sagy, Ben-Gurion University of the Negev, Beersheba, Israel.

Translation and cross-cultural adaptation

The processes of translation and cross-cultural adaptation were conducted according to the WHO’s official process of translation and adaptation of research instruments (WHO, 2013). First, each of five researchers independently translated the instrument from English to Swedish. Then, they discussed and agreed on a first draft version. A fluently bilingual person next compared the Swedish version with the English original; then, an independent authorized translator performed a back-translation. The two Swedish versions were compared, and after some minor corrections the translated version was pretested with a group of 15 teachers and administrative staff at a university. Based on the results, to minimize the risk of confusing the participants, the response scale was reversed for six items so that all items pointed in the same direction (higher scores indicating stronger perceived family sense of

coherence). The pre-test also led to some response alternatives being further clarified to represent more distinct alternatives. These revisions were discussed and made in consensus with Dr Sagy. This procedure was conducted prior to the conception of this thesis, without the author's participation.

Examination of content validity

Cognitive interviews (Willis, 2015) were used to evaluate the content validity of the S-FSOC-S from persons' with cancer and family members' perspectives; also, the content validity index (CVI) (Polit & Beck, 2006) was used to gain the perspective of experts.

Cognitive interviews

To evaluate the content validity from the perspective of the persons with cancer and family members', cognitive interviews were used with the methodology of think aloud (Willis, 2015). The inclusion criteria were having Swedish as the native language, aged ≥ 18 years, and living with cancer in the palliative phase in the family. Purposive inclusion was used to achieve variety in sex, age, education level, and time living with cancer. Persons with cancer were recruited between April and May 2014 by nurses at an oncology day-care unit; nine persons with cancer and one family member agreed to participate. The characteristics of the participants are shown in Table 4. Those who wanted to participate sent back their telephone number in a pre-stamped envelope. In all, five interviews were conducted in the participants' homes and five interviews at the hospital during chemotherapy treatment, all by the author; all interviews lasted between 17 and 35 minutes. The participants were explicitly instructed to 'think aloud' as they answered the S-FSOC-S item by item; that is, they read each item aloud and then continued to discuss aloud among themselves how they arrived at a particular answer. Clarifying questions were also asked, for instance, 'Can you tell me more about what you are thinking.' During and after each interview, field notes were written to identify whether any item was hard to understand. The responses were evaluated in terms of the English version of the instrument to make sure that the intended meaning was still reflected. Then, the transcribed interviews, together with the researcher's field notes, were analysed item by item to identify potential problems and difficulties understanding questionnaire items, alternative answers, words, or concepts (Willis, 2015).

Table 4. Characteristics of participants in cognitive interviews (n=10).

Sex, n		
	Male	4
	Female	6
Age (years), mean (SD) [Range]		58.8 (9.4) [41-73]
Years since diagnosis, mean (SD) [Range]		7.4 (4.2) [4-16]
Education, n		
	Up to high school (12 years)	6
	University	4
Occupation, n		
	Long-term sick leave	5
	Retired	5

Content validity index

Ten Swedish experts, professors or senior researchers with extensive knowledge of sense of coherence and the theory behind it, were invited to assess the CVI of the S-FSOC-S; seven of them did so. All experts rated each item from 1 to 4 on relevance to sense of coherence, where 1 stands for *not relevant* and 4 stands for *highly relevant*. CVI was calculated at the item level (CVI-I), and at the scale level (CVI-S). CVI-I was computed for each item by dividing the number of experts giving a rating of either 3 or 4 by the total number of experts. By summing the average CVI-I and dividing by the number of items, CVI-S was calculated. The suggested cut-off score of > 0.78 for CVI-I and > 0.90 for CVI-S was used (Polit & Beck, 2006).

Revisions of S-FSOC-S after examination of content validity

The cognitive interviews indicated that the questionnaire instructions required clarification and that there were problems with four items (2, 3, 4, and 7). These four items also had CVI-I scores below 0.78, as the experts considered them problematic for conceptual reasons, and poorly connected to the theory of sense of coherence. The CVI-S was 0.86 for the whole scale; items 2, 3, 4, and 7 were adapted to better suit the Swedish language while being as faithful as possible to sense of coherence theory (Table 5). However, the cognitive interviews provided evidence confirming that the Swedish translations had been accurately understood in relation to the intended meaning of each item.

Table 5. Changes made in S-FSOC-S after Cognitive interviews and CVI.

S-FSOC-S		
Items	Response alternative	Changes
1 To what extent do you have the feeling that you can influence what happens in your family?	1 not at all 7 to a great extent	No changes
2 When you have to do something, which requires the cooperation of all of the members of your family, you have the feeling that it:	1 surely wouldn't get done 7 surely would get done	No changes*
3 Until now your family life has had:	1 no clear goals and purpose 7 very clear goals and purpose	Until now, to what extent do your family life has had meaning? 1 not at all 7 to a great extent
4 To what extent has it seemed to you that your family rules are clear to you?	1 the family rules are not clear at all 7 the family rules are completely clear	No changes*
5 When your family faces a difficult problem, you usually feel that choosing a solution is:	1 it is always embarrassing, difficult and confusing to find a solution in the family 7 it is always completely clear in the family	No changes
6 Your family life seems to you:	1 completely routine 7 full of interest	To what extent is your family life spontaneous? 1 not at all 7 to a great extent
7 To what extent is the future of your family clear to you and can you anticipate what the family will be like five years from now?	1 I have no idea what the future of the family will be 7 the future of the family is completely clear	To what extent is the future of your family clear to you? 1 not at all 7 to a great extent
8 Do you have the feeling that you are being treated unfairly by your family?	1 very often 7 very seldom or never	No changes
9 When you think about your family, you very often:	1 ask yourself why you exist at all 7 feel how great it is to be alive	No changes
10 Doing the things, you do in the framework of your role in the family is:	1 a source of pain and boredom 7 a source of deep pleasure and satisfaction	<i>Doing things together in the family is:</i> 1 a source of pain and boredom 7 a source of deep pleasure and satisfaction
11 Does it happen that you have the feeling that you don't know exactly what will happen in your family?	1 very often 7 very seldom or never	No changes
12 Has it ever happened that people in your family on whom you counted on disappointed you?	1 always happened 7 never happened	No changes

*the problems that were experience in CVI and the cognitive interviews were due to the Swedish translation.

Psychometric evaluation

Participants

The recruitment period was between May 2015 and October 2016. The inclusion criteria were persons diagnosed with cancer in the palliative phase, aged 18 years or older, with the ability to speak and read Swedish, and willing to invite one additional family member to participate. A family member was defined as a person to whom the person with cancer felt linked to by a sense of belonging and engagement in their life, such as a spouse, sibling, child, or friend (Wright & Leahey, 2013). Inclusion criteria for family members were the ability to read and understand Swedish. Nurses in the care units consecutively recruited persons with cancer who met the inclusion criteria. All persons with cancer received oral and written information about the study and were asked to complete a questionnaire; furthermore, the person with cancer received a questionnaire to give to one family member. Participants also received pre-stamped envelopes to use when returning completed questionnaires. The questionnaire could also be completed on the Internet. No reminders were sent for ethical reasons. A total of 650 persons with cancer in the palliative phase were invited to participate along with one family member; of these, 179 (27.5%) agreed to participate together with 165 (25.4%) family members. Of the entire sample, 60 persons with cancer and 54 family members agreed to complete the S-FSOC-S a second time within a two-week period in order to evaluate the test-retest reliability. The retest was sent out 1.5 week after the completed questionnaire was received. There were 11 (6.1%) persons with cancer and 13 (7.9%) family members who completed the questionnaire online. The characteristics of the participants are shown in Table 6.

Table 6. Characteristics of participants in psychometric evaluation III and study IV.

	Persons with cancer	Family members
Sex, n (%)		
Male	88 (49.2)	58 (35.2)
Female	91 (50.8)	107 (64.8)
Age (years), mean (SD) [Range]	67.9 (10.3) [39-86]	62.1 (13.6) [15-91]
Years since diagnosis, mean (SD) [Range]	4.9 (4.9) [0-29]	
Marital status, n (%)		
Married/ cohabiting	141 (78.8)	147 (89.1)
Single	38 (21.2)	18 (10.9)

Data collection

The questionnaire included one section for demographic data and one section with three self-rating instruments: S-FSOC-S, Herth Hope Index (HHI-S) and Hospital Anxiety and Depression Scale (HADS).

Herth Hope Index (HHI-S)

The HHI-S (Herth, 1992) was developed to measure self-rated hope. The Swedish version has shown satisfactory psychometric properties in a palliative context (Benzein & Berg, 2003). It consists of 12 items, all answered on a Likert-type scale ranging from 1 'strongly disagree' to 4 'strongly agree'. An example of an item is 'I have a deep inner strength'. Negatively worded items are reversed. The total score ranges from 12 to 48; a higher score indicates a higher level of hope. The internal consistency measured with ordinal alpha was 0.86 for persons with cancer and 0.88 for family members in the present study.

Hospital Anxiety and Depression Scale (HADS)

The HADS (Zigmond & Snaith, 1983) measures anxiety and symptoms of depression and was used to assess psychological distress in persons with cancer and their family members. The HADS has shown satisfactory psychometric properties (Annunziata, Muzzatti, & Altoe, 2011; Gough & Hudson, 2009), has been translated to Swedish (Gotze et al., 2016; Gough & Hudson, 2009; Holm et al., 2016; Nappa, Lundgren, & Axelsson, 2016; Rodrigues et al., 2016). The HADS consists of 14 items, 7 measuring anxiety (HADS anxiety) and 7 measuring symptoms of depression (HADS depression); they are rated on a response-scale from 0 to 3. The total score on both subscales thus ranges from 0 to 21, and higher scores indicate higher levels of anxiety and symptoms of depression respectively (Zigmond & Snaith, 1983). The internal consistency of the HADS, as measured with ordinal alpha, was 0.91 for anxiety and 0.90 for symptoms of depression for persons with cancer and 0.89 for anxiety and 0.84 for symptoms of depression for family members in this study.

Data analysis

Data were analysed using IBM SPSS Statistics 23.0 (IBM Corp, Armonk, NY, USA), Stata 14.2 (Stata Corp, College Station, TX, USA) and R 3.3.2 (the R Foundation for Statistical Computing, Vienna Austria). The level of significance was set at $p < 0.05$.

Descriptive statistics were used to present background characteristics of the participants and study variables. Data quality was evaluated by analysing the

distributions of item and scale scores. Kurtosis and skewness statistics were used to describe the shape of the distribution of items (Altman, 1991). A normal distribution has a skewness value close to 0 and a kurtosis value close to 3. To test if the scale score was normally distributed, the D'Agostino test was used (D'Agostino, Belanger, & D'Agostino, 1990). Based on a polychoric correlation (ρ), homogeneity was examined using inter-item and item–total correlations. The internal consistency reliability was estimated by ordinal alpha (equivalent to Cronbach's alpha) (Gadermann, Guhn, & Zumbo, 2012; Streiner, 2003). A pooled sample including both persons with cancer and family members was used when evaluating test-retest reliability, with absolute agreement (%) and quadric weighted kappa statistics (κ_w). At the scale level, intraclass correlations (ICC) (two-way mixed-effects model) were used. The ICC statistics were interpreted as: <0.5 poor, 0.5-0.75 moderate, 0.75-0.9 good and >0.9 indicate excellent reliability (Koo & Li, 2016). Spearman's correlations (r_s) were used to evaluate construct validity when examining the associations between the S-FSOC-S, HHI-S and HADS. To support construct validity, S-FSOC-S was expected to be moderately correlated with HHI-S (≥ 0.3) and HADS (≥ -0.3).

Study IV

Participants and data collection

The participants and data collection were the same as in the psychometric evaluation presented in study III (Table 6).

Data analysis

The level of statistical significance was set at $p < 0.05$. Data were analysed using SPSS statistics 23.0 (IBM Corp., Armonk, NY, USA) and Stata 14.2 (Stata Corp, College Station, TX, USA).

To describe demographic data and study variables, descriptive statistics were used. Linear regression analyses were performed in two blocks to determine if family sense of coherence was associated with hope, anxiety, or symptoms of depression. In these models, the outcome variables were HHI-S, HADS anxiety, and HADS depression scores. Separate regression analyses were performed for each group due to the fact that family members were nested into persons with cancer. In the first block, family sense of coherence was included as a single explanatory variable. Thereafter, in the second block a set of covariates were

added: for the persons with cancer, age, sex, education, marital status, cancer duration, and having children at home, and for the family members, the same except that cancer duration was changed to relationship to the person with cancer. According to the variance inflation factor (VIF mean = 1.42 for persons with cancer and 1.97 for family members) no problems with multicollinearity were observed. As the assumptions regarding normally distributed residuals and homoscedasticity were violated, all regression models were ultimately confirmed using robust regression analyses with robust standard errors (Huber-White sandwich estimate of variance).

Ethical considerations

Families living with cancer in the palliative phase may be viewed as a vulnerable study population, generating many challenges to research. However, it is necessary to involve individuals as well as families living with incurable cancer in research studies in order to improve palliative care (Aoun et al., 2016; Terry et al., 2006). With respect to autonomy, all potential participants should have the opportunity to decide for themselves whether or not to participate in studies when they meet the inclusion criteria (Terry et al., 2006). The studies in this thesis were designed and conducted in accordance with the World Medical Association Declaration of Helsinki (WMA, 2013) and Swedish ethics legislations (SFS). The principles of autonomy, beneficence, and justice were upheld throughout the process, from designing the studies to data collection, analysis, and documentation (Casarett, Knebel, & Helmers, 2003). The studies were approved by the Regional Ethical Review Boards in Lund (study I – No. 271/2006, 80/2007, 2010/484, and 2011/754) and in Linköping (study II-IV- No. 2014/70-31). Furthermore, all studies were approved by each relevant clinical department head. All participants were informed about the purpose of the studies, that their participation was voluntary, that they could withdraw at any time without any specific reason, and that all material would be kept confidential. Before the interviews (II–III), all participants signed a written consent form, and throughout the interviews, the participants themselves decided what they wanted to share. For the questionnaires (III–IV), participants were assumed to have consented to participate if the questionnaire was completed and sent back to the researcher. To ensure the confidentiality of the collected data, the mp3-recordings, transcripts and the questionnaires were coded by numbers, kept separately from the participants' names and addresses. All data were stored in a locked space, which only the author had access to.

Results

In this section, the main results from the four studies will be presented. The results from the studies contribute to both a general and a detailed picture of health and family sense of coherence for families living with cancer. This can be seen in how health and family sense of coherence can be viewed both as a shared experience from the perspective of the family as a unit (II) and as a measurable variable from an individual perspective (I, II, IV).

The partner's health (I)

Increased diagnoses for partners after the cancer diagnosis

One year after the cancer diagnosis, the partners had significantly more mood disorders (F30-F32), reactions to severe stress (F43), and ischemic heart disease (I20-I25) than they had in the year before the diagnosis (Table 7). More specifically, for partners, increases were shown for reactions to severe stress and adjustment disorders (F43), mild depressive episodes (F32), acute myocardial infarction (I21), and contact with health services (Z00-Z99) during the first two years after the cancer diagnosis.

Table 7. List of the diagnoses that increased the most among partners of persons with cancer.

Diagnosis of partner (ICD 10 diagnoses)	One year post-diagnosis vs /One year pre-diagnosis	
	RR	95% CI
Mood [affective] disorders [F30-F32]	1.83	1.65 – 2.01
Reaction to severe stress, and adjustment disorders [F43]	6.94	6.33 – 7.56
Ischemic heart diseases [I20-I25]	1.09	1.00 – 1.18
Cerebrovascular diseases [I60-I69]	1.15	0.99 – 1.30

RR: risk ratio. CI: confidence interval. A quotient equalling 1.0 indicates that diagnoses were equally common among PCAs one year post-diagnosis and one year pre-diagnosis.

Increased health care use and health care costs for partners after the cancer diagnosis

Partners' increased health care use and health care costs varied according to the type of cancer that had been diagnosed. Male partners had greater rise in health care use and health care costs one year after the cancer diagnosis. Generally, inpatient care increased more than outpatient care for both the first and second

year after the cancer diagnosis. Specifically, there were significant increases in inpatient care one year after the cancer diagnosis for partners of persons with liver (RR=2.14), lung (RR=1.46), colon (RR=1.41), and miscellaneous other cancers (RR=1.53). Moreover, increased psychiatric outpatient care was observed during both the first and second years after the cancer diagnosis. Furthermore, no overall difference in health care use was seen which could be related to the partners' ages.

Partners of persons with cancer had respectively 6% and 7% higher health care costs one and two years after the cancer diagnosis than partners of controls with no cancer. This applied in particular to partners of persons with liver (40%), gastric (24%), colon (17%), and lung cancer (7%) one year after the cancer diagnosis. Also, comparing health care costs one year prior to cancer diagnosis versus one year after it revealed increases for both inpatient and outpatient care for partners of persons with liver and miscellaneous other cancers.

Familial interaction patterns during the palliative phase (II)

To achieve balance and well-being in their life situation, the families adjust to meet changes and to increase their ability to deal with family life in their new circumstances. These adjustments were reflected in the data as changed interaction patterns in the families. One overall pattern was revealed, 'adjusting the family interaction pattern to changes in family life', together with three interrelated interaction patterns: (1) 'power dynamics in the family', (2) 'the "secret game" in the family', and (3) 'multifaceted closeness and distance in the family'. These patterns could appear separately or together depending on the situation and the persons involved. Moreover, the family members also had the threat of mortality on their minds, and it was no longer possible to behave normally once they knew the cancer was incurable; instead, they changed their way of interacting so as to not hurt each other. This might have contributed to some discontent on the part of the persons with cancer, who may have felt that they were not being treated the same as before the cancer diagnoses was deemed incurable.

Power dynamics in the family

The person with cancer was given increased power in the family, and his/her needs and wishes largely decided how the family would interact during the time

they had left together. In particular, regarding decision-making, the person with cancer gave power to, or took power from, other family members, who for their part played a corresponding or inverse role in this 'give and take'. Family members put their own needs and wishes aside to do everything they could to let the time they had together as a family be the best possible. This could jeopardize their well-being if the palliative phase lasted for a long time. Moreover, the different positions the family members took were dependent on the situation. The person with cancer could experience frustration when given the power to decide what the family should do in everyday life, which degraded their well-being. Family members could also experience frustration when they felt forced to give or receive power when it was not in line with their wishes.

The 'secret game' in the family

Both persons with cancer and their family members avoided conflicts and hid concerns from each other, like a 'secret game'. The way each member played this 'secret game' depended on the importance of the particular situation; both persons with cancer and family members were particularly careful to avoid communicating their thoughts about certain 'forbidden' areas. For the persons with cancer it was important to feel that they were being treated as they had used to be. When the person with cancer was being treated in an unusual manner it did not always help their well-being. However, if a family member had the courage to confront or discuss issues within the family, this was likely to be the moment that changed familial perceptions regarding their situation.

Multifaceted closeness and distance in the family

How family members interacted with each other can be characterized with a multifaceted lens of closeness and distance, especially when the ill person's symptoms worsened and affected the family's daily life. Changes in closeness and distance were observed when the persons with cancer chose whom they wanted to have a close or distant relationship with; family members also made these choices in relation to the person with cancer. Sometimes, the person with cancer felt forced to actively create a distance from certain family members in order to feel as good as possible, but at the same time this distance could make the person with cancer feel frustration and sadness. Many family members wanted to have more and deeper contact with their ill relative; adult children in particular sometimes desired to be more involved in their ill parent's life. Moreover, families needed to prioritize what was most important for the entire family. They tried to be 'in the moment' and have more short-term aims, in

order to have something to hope for. All in all, the families adjusted what they wished and hoped for; just finding time to be together was often enough.

Evaluation of the short version of the Family Sense of Coherence scale among persons with cancer in the palliative phase and their family members (III)

The results showed that the translated and adapted Swedish version of the S-FSOC-S is conceptually and semantically equivalent to the original English version, demonstrating linguistic validity, acceptable reliability, and excellent consistency.

All items of the S-FSOC-S demonstrated skewed distributions with ceiling effects, for both persons with cancer and for family members. No data were missing in the completed questionnaires. The S-FSOC-S total scale had a significant, negatively skewed, peaked distribution for both persons with cancer (skewness = -1.06, kurtosis = 3.74, $\chi^2(2) = 23.0$, $p < 0.001$) and family members (skewness = -1.07, kurtosis = 4.29, $\chi^2(2) = 24.2$, $p < 0.001$). For both persons with cancer and family members, there were satisfactory inter-item correlations, and the item–total correlation, with no correlations below 0.3. The internal consistency reliability measured with ordinal alpha was excellent (0.91 for both groups) and could not be improved by removal of any item from the scale (ordinal alpha if item deleted). The test-retest reliability was, in general, satisfactory and absolute agreement had a range between 93.0 and 95.8% on item level (Table 8). On scale level intraclass correlations for single measures were 0.64 (95% CI, 0.52-0.74).

Table 8 Test-retest reliability for items in the Family Sense of Coherence scale (pooled sample n=114).

Items	Absolute agreement, %	K _w (95 % CI)
1 To What extent do you have the feeling that you can influence what happens in your family?	93.3	0.55 (0.37-0.70)
2 When you have to do something, which requires the cooperation of all of the members of your family, you have the feeling that it:	93.0	0.46 (0.29-0.61)
3 Until now, to what extent do your family life has had meaning?	95.8	0.37 (0.19-0.59)
4 To what extent it seemed to you that your family rules are clear to you?	95.2	0.52 (0.36-0.66)
5 When your family faces a difficult problem, you usually feel that choosing a solution is:	94.3	0.42 (0.23-0.58)
6 To what extent do your family life influences of spontaneity?	95.1	0.59 (0.43-0.72)
7 To what extent is the future of your family clear to you?	93.6	0.63 (0.47-0.76)
8 Do you have the feeling that you are being treated unfairly by your family?	95.4	0.49 (0.30-0.66)
9 When you think about your family, you very often:	92.6	0.36 (0.18-0.56)
10 Doing things together in the family is:	94.9	0.45 (0.21-0.69)
11 Does it happen that you have the feeling that you don't know exactly what will happen in your family?	94.8	0.57 (0.43-0.70)
12 Has it ever happened that people in your family on whom you counted on disappointed you?	94.0	0.61 (0.47-0.75)

Interpretation of weighted kappa statistics (k_w): <0.20 reflects poor agreement, 0.21–0.40 is fair, 0.41–0.60 is moderate, 0.61–0.80 is good, and 0.81–1.00 is very good.

The correlation pattern between S-FSOC-S, HHI-S, and HADS supported construct validity. For persons with cancer, S-FSOC-S scores correlated positively with HHI-S ($r_s = 0.50$, $p < 0.001$) and negatively with HADS scores (anxiety: $r_s = -0.38$, $p < 0.001$, depression: $r_s = -0.46$, $p < 0.001$), as hypothesised. A similar trend in correlations was seen for family members, with S-FSOC-S scores correlating positively with HHI-S ($r_s = 0.60$, $p < 0.001$) and negatively with HADS scores (anxiety: $r_s = -0.38$, $p < 0.001$, depression: $r_s = -0.41$, $p < 0.001$).

Associations of family sense of coherence with hope, anxiety, and symptoms of depression respectively (IV)

Overall, family sense of coherence was significantly, independently associated with hope, anxiety, and symptoms of depression for both persons with cancer and family members. In block I, stronger family sense of coherence was associated with greater hope and lower anxiety and symptoms of depression. The proportion of variance in the outcome variables that was explained by family sense of coherence ranged between 14% and 23% for persons with cancer and 15% and 28% for family members. These associations remained in the full model (i.e. block II) after the covariates were entered, which explained between 23% and 26% for persons with cancer and between 20% and 30% of the total variance for family members. Moreover, among the covariates, female sex was associated with higher levels of anxiety for both persons with cancer and family members. In addition, working was significantly associated with greater hope and lower anxiety for persons with cancer.

The findings from the regression analyses were replicated with robust regression. These models demonstrated equivalent findings to those of the models without robust standard errors and are therefore not further reported.

Discussion

Consequences for families when living with cancer

Families changed their interaction patterns when living with cancer in the palliative phase in order to feel as good as possible in the time they still had together (II). This was revealed within the interaction patterns *power dynamics in the family*, the *'secret game' in the family*, and *multifaceted closeness and distance in the family* (II). The *power dynamics in the family* were manifested in a give-and-take process between family members. This distribution of power is an integral element in every family, whether or not family members choose to acknowledge it (Van Der Westhuizen, 1981). Nevertheless, someone's increased power has to be compensated by someone else giving (voluntarily or involuntary) their power away (Kuokkanen & Leino-Kilpi, 2000). Moreover, both persons with cancer and their family members chose in which situations they would be more passive or active regarding power distribution (II); this is in line with the ideas that each person is part of his/her own power structure (Van Der Westhuizen, 1981) and that choices of power strategy depend on motivational and situational factors (Pierro, Cicero, & Raven, 2008) as well as with the following definition of power: 'the extent to which a person decides or affects another's behaviour' (Van Der Westhuizen, 1981).

The *'secret game' in the family* was an ongoing process within each family, played mostly because they did not want to hurt each other. It can be confusing how one should behave when a family member has advanced cancer (Sandgren, 2012), which could explain why the families in our study did not act as they usually would have before the cancer diagnosis. Furthermore, secrets have been described as magnets within family relationships, attracting some members while repelling others. That is, secrets create a complex web of repetitive interactions, shaping contours of proximity and distance within various relationships (Imber-Black, 2014).

The *multifaceted closeness and distance within the family* showed that both closeness and distance, in different cases and stages, were required to achieve the best possible familial well-being, and were chosen by either the person with cancer, their family members, or both (II). The results are consistent with earlier studies showing increased closeness when living with cancer in a palliative phase (Carlander et al., 2011; Garcia-Rueda et al., 2016; Lim, Paek, & Shon,

2014; Persson et al., 2008) and a chosen distance, were the family members were withdrawing from each other (Drabe et al., 2016). Moreover, the fact that family members do not know how much time they have left together may encourage some families to place more value on their time spent together (ibid). However, sometimes these changes in interaction patterns may decrease well-being in the families, especially if the palliative phase has lasted for a long time. Therefore, these families may need professional support to avoid or reduce decreased well-being.

Consequences for partners when living with the person with cancer

Partners had an increased risk for poor mental health according to the diagnosis they received: affective mood disorders [F30-F32] and reaction to severe stress [F42], both one and two years after the cancer diagnosis (I). Similarly, previous studies have found increased psychosocial distress and psychiatric morbidity among the partners and other family members of patients with cancer (Drabe et al., 2008; Given et al., 2012; Hagedoorn et al., 2008; McClure et al., 2012; Nakaya et al., 2010; Rhee et al., 2008; Sjøvall et al., 2009). In addition, family members may often feel overloaded with obligations and the shifting roles they need to quickly and responsively pick up (Wozniak & Izycki, 2014), which may contribute to family members' increased risk of psychological distress (Hagedoorn et al., 2008), especially when the patient's physical symptoms worsen (Given et al., 2012; Grunfeld et al., 2004; Heins et al., 2013; Nakaya et al., 2010; Rhee et al., 2008). Moreover, the high mortality rates of certain cancer types also may increase the risk of poor mental health (Ji et al., 2012), as uncertainty is difficult and is a driver for anxiety (Hendriksen et al., 2015). This may be understood in terms of the interdependent relationship within the family system (Wright & Leahey, 2013) between psychological distress reported by the person with cancer and that by their family members (Hagedoorn et al., 2008; Hodges, Humphris, & Macfarlane, 2005). Sometimes, in contrast, partners do not become as highly affected by the distress of the person with cancer, as the partner affects the person with cancer (Rottmann et al., 2015). Of course, a person with cancer and their family members do not necessarily react in the same way (Tuinstra et al., 2004), but it is common for families to experience various levels of anxiety and depression during the cancer trajectory (Hagedoorn et al., 2008; Zabora et al., 2001).

One diagnosis that increased significantly for partners of persons with cancer were ischemic heart disease (I), as also shown in previous studies (Ji et al., 2012; Sjøvall et al., 2009). Ji et al. (2012) found that partners of persons with pancreatic and lung cancer were at particular risk of coronary heart disease. These diagnoses have a very poor prognosis, making the life situation very stressful for the partners (Wozniak & Izycki, 2014). Even other cancer types have high mortality rates, which may increase the risk of coronary heart disease for partners (Ji et al., 2012).

Partners have increased health care use both one year and two years after the cancer diagnosis, varying according to the type of cancer that has been diagnosed (I). Moreover, for partners of persons with liver, lung, colon, and other miscellaneous cancers, there was a higher risk of increased health care use (I). This could indicate that partners of persons with cancer diagnoses that have poorer prognoses as well as higher severity have elevated risk of ill health—in line with earlier research, which has shown that ill health in the family is especially elevated when patients' physical symptoms worsen (Given et al., 2012; Grunfeld et al., 2004; Heins et al., 2013; Nakaya et al., 2010; Rhee et al., 2008). These results may be considered in the light of the stressful life situation of persons with cancer after their diagnosis, living together with others alongside an uncertain outcome. Stress may contribute to a smaller or greater family crisis when accustomed behaviours are not effective to manage the life situation (Denham et al., 2016), and this may shake the family's foundation and increase disorganisation in the family (ibid). This is in line with the view of the family as a system whose parts mutually impact each other, and whose interactions, relationships, and reciprocity are of great significance for the well-being of each individual within the system (Benzein et al., 2017). Thus Thus, the individual family members and the family as a unit are affected simultaneously (Denham et al., 2016), and there is a need for individual family members and the family as a whole to identify their resources and weaknesses and use them wisely to increase their well-being—this may decrease the risk for ill health in the family. Logically, the more influence an illness has on individual family members, the more the family will have to deal with changes in the family systems (which make up the sum of individual changes and resulting changes to relationships) (ibid). These changes in family systems aim to minimize the experience of ill health in the family (Bell, 2013).

Consequences for health care

Higher health care costs were seen in partners of persons with cancer both one (6%) and two years (7%) after the cancer diagnosis compared to the control group (I), especially in partners of persons with liver, gastric, colon, and lung cancer. This result corresponds with earlier research involving lung and colon cancer diagnoses, which showed significantly increased costs of health care utilization for partners after compared to before the cancer diagnosis (Sjölander, 2012; Sjøvall et al., 2009). It should also be considered that there are hidden health care costs in families living with cancer who provide care to the person with cancer in their homes (Sjölander, 2012). This is a challenging issue for the health care services, as this cost is difficult and seldom measured. Persons with cancer have the need for both practical and social support from their family members, and therefore it is crucial that family members stay as healthy as possible (Emslie et al., 2009). This is a strong argument for health care services to support the use of a family focus to promote family health, well-being, and relief from illness suffering (Bell, 2009).

Family sense of coherence

Stronger perceived family sense of coherence was associated with lower anxiety and symptoms of depression for both persons with cancer and family members (IV), due to their ability to manage the life situation. Similar associations have been shown between family sense of coherence and psychological distress among childbearing couples (Ngai & Ngu, 2013, 2014). Family sense of coherence was most strongly associated with hope for persons with cancer as well as for their family members (IV). Hope and meaningfulness (which are one factor in sense of coherence) may be seen as interrelated when described theoretically (Post-White et al., 1996). Hope has been broken down into overall, generalized hope (e.g. 'hope that things will be all right') and as more concrete, particularized hope (e.g. 'hope that chemotherapy will be successful') (Dufault & Martocchio, 1965). Hope has been shown to be required for high family quality of life (Alidina & Tettero, 2010) and well-being (Benzein & Berg, 2005). To achieve family well-being families were engaged in activities with each other in order to just spend time together (II). Being together and keeping good relationships among family members is especially important during the late palliative phase (Yamashita et al., 2017). Therefore, health care services should find ways to support families to have a meaningful life and maintain hope even during the palliative phase.

Perceived family sense of coherence at the individual level for persons with cancer in a palliative phase and their family members can be measured with S-FSOC-S (III), shown here to be conceptually and semantically equivalent to the original English version and to have linguistic validity, reliability, and excellent consistency in the assessed setting (III). Internal consistency was comparable to earlier studies using FSOC-S (Andersson, 1998; Cecen, 2007; Moen & Hall-Lord, 2016; Ngai & Ngu, 2011; Sagy, 1998). While in study III ordinal alpha (Gadermann et al., 2012) was used, since data were non-normally distributed, previous studies have used Cronbach's alpha; nevertheless, the results were similar, indicating that FSOC-S is reliable in various contexts. The decision to change all items to point in the same direction may have increased the reliability (Weijters & Baumgartner, 2012).

The high perception of family sense of coherence, causing the skewness, may indicate that the majority of the persons with cancer and family members manage their life situation without too much struggle. As expected, the hypotheses regarding construct validity were supported, with negative relationships between family sense of coherence and (respectively) anxiety and symptoms of depression and a positive relationship with hope (IV). This indicates that persons with cancer and family members with a strong family sense of coherence are more likely to approach the demands of living with cancer in the palliative phase as challenges, rather than stressors. This is in line with Antonovsky's (1987) suggestion that family sense of coherence has a stress buffering effect, which may help persons with cancer and family members to handle their life situation. Furthermore, family sense of coherence can strengthen resilience in stressful situations and protect against the development of anxiety and depression (Antonovsky & Sourani, 1988). This also helps the families conceptualize the world as organized and understandable, which plays an important role in their perception of the challenges faced (ibid).

Methodological considerations

In this thesis, the research questions were approached using both qualitative (II, III) and quantitative (I, III, IV) methods in order to achieve breadth and depth of coverage of the research topic (van Griensven, Moore, & Hall, 2014).

Trustworthiness (II, III)

Qualitative studies can be assessed by means of the quality-affirming concept of trustworthiness, which comprises credibility, confirmability, dependability, and transferability (Polit & Beck, 2012).

Credibility refers to the truth and the believability of the data and whether the results are based on faithful descriptions and are tenable (ibid). Various aspects of the research process need to be considered, such as the sample, interviews, and how the data are interpreted (ibid). The first effort to strengthen credibility in this thesis was to collect family members with a variety of relationships to the persons with cancer, to encourage them to choose more than one family member, and to select families living with cancer in both early and late palliative phase. The second effort to strengthen credibility was to invite all families to a second interview. However, all families declined the request due to unwillingness, practical circumstances and other circumstances related to the illness. A second interview were in line with Gadamer's assertion that the understanding of family members and researchers changes over time (Fleming et al., 2003). Aside from capturing such changes, the use of multiple interviews allowed families the opportunity to explore certain issues in greater depth and to finish uncompleted reflections, and also gave the interviewer the opportunity to further explore certain issues (Astedt-Kurki, Paavilainen, & Lehti, 2001). Another factor strengthening credibility was the focus on creating fertile conditions for the interviews (Votelen, Konradsen, & Ostergaard, 2017), where the persons with cancer themselves chose the other family member(s) who should be included and chose the location for the interview. This was expected to facilitate an open climate and the comfort to talk to each other within the interview, as has been seen in earlier studies using family interviews (Arestedt et al., 2016; Arestedt, Persson, & Benzein, 2014; Bylund, Benzein, & Persson, 2013; Fjose et al., 2016). To further strengthen credibility, a detailed description of all parts of the research process was provided together with continued discussion of the interpretations within the research group, to ensure that familial perspectives were represented as clearly as possible (Austgard, 2012). There were also threats to credibility, issues that may not have been captured due to the self-selected sample, negative influence on the depth of the interviews due to the lack of second interview with the families, and the fact that families were interviewed about their overall experiences when the specific interest was interactions in the family.

Confirmability refers to the objectivity or neutrality of the data, reflected in the level of agreement between two or more independent people about the data's relevance or meaning (Polit & Beck, 2012). To ensure confirmability the data included interviews, observations, field notes together with description of all parts of the research process. which also are essential for the interpretation of family level data (Eggenberger & Nelms, 2007). To make new understanding possible, researchers need to recognize their own prejudices (Gadamer, 2004), which reflects one's own history and prejudices which one never can renounce (ibid). This recognition of prejudices composes the foundation of the dialectical movement shifting between the whole and the parts in order to facilitate understanding (the hermeneutical circle). During the analyses, the researcher constantly questioned the abstractions and interpretations of the data. Furthermore, continuous discussions of the interpretations occurred within the research group, to ensure that familial perspectives were represented as clearly as possible (Austgard, 2012).

Dependability refers to whether the interpretations are stable over time and whether they are representative (Polit & Beck, 2012). The same researcher conducted all interviews, which were also guided by the same main questions; these conditions should strengthen the dependability of the study.

Transferability refers to the extent to which the results can be transferred to other populations and contexts (ibid). Efforts were made to provide detailed description of the families and identify similarities with previous studies to strengthen the transferability of the results beyond families living with cancer in a palliative phase. Moreover, the inclusion of family members and families, predominantly of Swedish origin, mean that transferability to populations from other cultures should be considered with caution.

In order to ensure trustworthiness when conducting the cognitive interviews, one effort was to choose the methodology of think aloud to ensure the participant's perspectives could be as fully as possible expressed (III). This approach has emerged as one of the more prominent methods for identifying problems with questions in a scale (Willis, 2015). To further facilitate the participants' possibility to express their understanding of the items they were asked to start reading each item aloud and then describe their internal process of answering each item (III). This way of managing the reading may not always be suitable due to difficulties to constantly put words to one's thinking (Willis,

2015), but that was not barrier in this study (III). Other efforts to strengthen trustworthiness were to collect participants with a variety in age, sex and education level and that the same researcher conducted all interviews.

Validity and reliability (I, III, IV)

Quantitative studies should be assessed in terms of *validity* and *reliability* (Polit & Beck, 2012), where validity refers to the believability and reliability to the repeatability of the results (ibid). Additionally, in relation to questionnaires, validity is the degree to which the instruments measures what it intends to measure, in relation to the studied population, aim, and dimensions of the instrument (Streiner, Norman, & Cairney, 2014).

Internal validity refers to the extent to which results are explained by the independent variable rather than other factors. In registry studies, such as (I), internal dropout is needed to be calculated with and when using well-documented registers this issue may be reduced. The Cancer Registry of Southern Sweden and the relevant inpatient and outpatient registries offer coverage that is almost complete (Barlow et al., 2009; Drummond et al., 2006); however, for the Health Care Registry of Southern Sweden there may be an issue of underreporting. Drop out during the study period might have occurred due to death, moving out of the region or receiving health care in another health care region. On the other hand, a strength of population studies in terms of validity is that they include all variances within the population (Altman, 1991). Furthermore, using a definition of partner that assumes that they live at the same address as the person with cancer may have excluded other family members who played important roles.

Low response rates often have consequences for *external validity* in empirical studies (IV), but this is seldom a problem in psychometric studies (III) as long as it does not lead to variation in the data, such as infrequent use of certain response alternatives (Streiner et al., 2014). The response rate in this study was low, 27.5% for persons with cancer and 25.4% for family members (study III, IV), which could partly be explained by the fact that no reminders were sent out and that the nurses involved in data collection were pressed for time given their main job duties. Furthermore, as no data were received from participants who declined to participate (III, IV), it was not possible to perform any type of analysis of reasons for dropout. Moreover, the low response rates (IV) may have affected the results, for example leading to an inaccurately positive picture due

to the exclusion of those who were most frail. Broadly, data show declining response rates in European countries as well as the United States over the last decade (Nilsson et al., 2007). Since response rate often is perceived as an important indicator of the quality of a survey, it is important for researchers to get as high a response rate as possible. Indeed, low response rates may have concrete consequences in terms of bias, threatening the representativeness and generalizability of survey data (Wenemark, 2010). It may have been preferable to try to increase the response rate in studies III and IV with additional follow-up, such as multiple reminders and provision of better information on the aim and benefits for future families including persons with cancer. However, while efforts to increase response rate may be successful for specific surveys, they do not seem to offer a long-term solution to declining response rates and may even lead to negative reactions among respondents, possibly reducing willingness to participate in similar studies in the future (ibid). Therefore, the researcher should think from the respondent's perspective when planning for a survey, and consider what motivates them not only to participate but also to be committed and answer questions carefully and thoughtfully.

Statistical conclusion validity is established by the use of instruments that are valid and reliable, and thus includes a psychometric aspect (Streiner et al., 2014). Both HHI-S and HADS have been psychometrically evaluated within a palliative context, while S-FSOC-S still need to be evaluated, which was part of the goal of this study. A stringent translation and validation process helped to establish the cross-cultural equivalence of S-FSOC-S; however, the factor structure of S-FSOC-S was not evaluated, which stands as a limitation. Earlier studies have concluded that Chinese (Ngai & Ngu, 2011) and Turkish (Cecen, 2007) versions of FSOC-S are unidimensional rather than multidimensional, and this also needs to be evaluated for the Swedish version (S-FSOC-S).

Statistical conclusion validity also refers to statistical methods and to what degree conclusions about relationships and variances exist in reality (Polit & Beck, 2012). This may be viewed from two angles: the risk of type I and of type II error (Altman, 1991). Type I error occurs when differences are detected in the data even though they do not exist in the population. The risk of type I error is determined by the p-value, which in these studies (I, III, IV) was set at 0.05 (5% risk), a commonly used limit. Type II error concerns the opposite risk, that of not detecting differences in the data even though they exist in the population (ibid). It is related to power, and hence sample size. In this research, power was

not calculated for any of the quantitative studies. All available people were used in the register study (I), and the sample was large: the smallest group compared contained 70 people, which was judged to be large enough to avoid type II error. Logistic regression is used to support inferences of associations between the independent and dependent variables (ibid). Furthermore, even where the response rate was low (IV), the sample size was adequate for the multiple linear regression models according to a post hoc calculation, showing a statistical power ($1-\beta$) of 0.98 for persons with cancer and 0.96 for family members, based on a medium effect size $f^2 = 0.15$, a significance level of 5% ($p < 0.05$) and 7 explanatory variables. However, it is preferable to perform a sample size calculation prior to the study, and the results have to be interpreted with this in mind.

Conclusions

Taking the results in this thesis all together, it can be concluded that a cancer diagnosis within a family affects both individual family members and the family as a unit. Within the family, family relationships are characterized by reciprocity, as shown when partners' health was affected when living together with a person with cancer. Furthermore, the type and severity of the cancer may indicate the partner's risk for ill health. In addition, families living with cancer in a palliative phase have the ability to adjust their familial interaction patterns to achieve balance and well-being. These changes increase the families' ability to deal with family life in new circumstances without hurting each other. When there are diverging wishes or opinions in the family, this can influence their well-being in a negative way, especially if the palliative phase lasts for a long time. The S-FSOC-S can be considered a useful instrument for assessing familial coherence from the perspective of persons with cancer in a palliative phase and their family members. Stronger family sense of coherence is associated with higher hope and with lower anxiety and symptoms of depression in both persons with cancer and their family members. Using the S-FSOC-S can help identify families with weak family sense of coherence, who may be in need of professional support to be able to manage their life situation. Understanding the complex dynamics and challenges families living with cancer encounter will lead to greater knowledge of how to tailor care to be the most beneficial it can be.

Clinical implications

This thesis yields knowledge that are helpful to health care providers working with families living with cancer. The family's needs to be endorsed and their inclusion in the caring process ensured by health care providers throughout the whole cancer trajectory can promote familial well-being. It is also necessary for health care providers to ask family members to be observant of early signs of ill health, in particular conditions for which family members are at high risk due to their stressful life situation, such as coronary heart disease. Also, familial interaction patterns need to be considered in order to identifying families at particular risk for poor adjustment. Since it is common for families living with cancer to experience various levels of decreased well-being, there is a need for health care services to provide suitable interventions in collaboration with

families needing professional support. For instance, individual- or family-targeted interventions such as health-promoting conversations could be required for families living with cancer who have an elevated risk of ill health and decreased well-being. The use of S-FSOC-S as a screening tool to identify families with weak family sense of coherence can be recommended in this regard as well. Health care providers could use its results to elicit discussion with families, discover their needs, and offer suitable interventions.

Future research

In order to develop effective family-focused care for families living with cancer, further investigations are required. Both quantitative and qualitative studies are needed to obtain more knowledge and deeper understanding of individual family members and the family as a unit, for example of how they affect, communicate and support each other in order to achieve family well-being. There is also a need for studies of how individual family members affect each other. Evaluation of different family-focused interventions, like health-promoting conversations, could strengthen the evidence of which interventions are the most optimal for families living with cancer. In addition, it is warranted to further evaluate how the S-FSOC-S can be used as a screening tool to identify families at risk for lower levels of well-being due to palliative care. Studies are also needed to increase the knowledge how family sense of coherence, reported by the individuals, affects other family member's experiences of hope, anxiety and symptom of depression. Finally, further research should target the focus of how early integrated palliative care should be implemented to obtain care at the highest quality.

Svensk sammanfattning

Bakgrund

I Sverige idag ses ett ökat antal cancerfall och minst var tredje person kommer att diagnostiseras med cancer under sin livstid. 2015 diagnostiserades 61 100 personer med cancer (Cancerfonden, 2017). Även om fler blir diagnostiserade med cancer så minskar risken att dö p.g.a. sin cancersjukdom (Socialstyrelsen, 2013). Dock är cancer den andra vanligaste dödsorsaken i Sverige idag. Men med förbättrad diagnostik, behandling och överlevnadsprognos lever fler med cancer under en längre tid (Socialstyrelsen, 2012). Denna trend syns även i övriga Europa (Ferlay et al., 2013). När en person diagnostiseras med cancer, kan den vara botbar eller obotbar då personen kan leva under kortare eller längre period med cancer. När cancer är obotbar är den i en palliativ fas som kan vara mellan dagar till flera år. Men kliniskt är det inte alltid så tydligt när cancer är botbar eller obotbar (Hansson et al., 2008). Livssituationen efter en cancerdiagnos påverkar hela familjen, men kanske på olika sätt för olika familjemedlemmar (Andersson et al., 2010; Missel & Birkelund, 2011; Northouse, 2012). Eftersom cancer är en livshotande diagnos tänker alla familjemedlemmar på sin egen och resterande familjs död (Carlander et al., 2011), vilket kan innebära att hälsan hos familjemedlemmarna påverkas, vilket även gäller för personen med cancer (Andersson et al., 2010; Blanchard et al., 1997; Pusa et al., 2012). Familjemedlemmarna har en viktig roll genom att bidra med emotionellt och praktiskt stöd till den person som diagnostiserats med cancer. Att vara familjemedlem kan innebära en ökad risk för psykisk (Goren et al., 2014; Sjøvall et al., 2009) och fysisk ohälsa (Sjøvall et al., 2009; Stenberg et al., 2010), kanske speciellt för partners. Vilket kan negativt påverka familjefunktionen och interaktionen mellan familjemedlemmarna. Ohälsa i familjen är framförallt framträdande när personens symtom från cancer förvärras och är i behov av palliativ vård (Given et al., 2012; Grunfeld et al., 2004; Heins et al., 2013; Nakaya et al., 2010; Rhee et al., 2008) och detta är förknippat med försämrad livskvalitet (Clark et al., 2010; Gao et al., 2010; Hagedoorn et al., 2008; Zabora et al., 2001). Tidigare forskning har visat att känslan av sammanhang främjar funktionen och välbefinnandet i familjen (Lustig & Akey, 1999; Ngai & Ngu, 2011) och förutspår livskvaliteten i familjen (Andersson, 1998; Hsiao et al., 2017) samt familjens upplevelser av psykologisk stress (Ngai & Ngu, 2014) i olika kontexter utanför den palliativa

vården. Eftersom många familjer har tillräckliga resurser att hantera sin livssituation när de lever med cancer finns det ett behov av att kunna identifiera vilka familjer som behöver professionellt stöd. Denna identifikation kan möjliggöras med ett validerat instrument, som avser att mäta som känsla av sammanhang i familjen.

Syfte

Det övergripande syftet var att undersöka hur familjer som lever med cancer erfar sin livssituation, med fokus på hälsa och känsla av sammanhang i familjen.

Metod

En kombination av metoder har använts, både kvalitativa (II, III) och kvantitativa (I, III, IV). Den första delstudien studerade påverkan på partners hälsa, genom att jämföra tiden före med tiden efter cancerdiagnosen. Med hjälp av populationsbaserade register och en logistisk regressionsanalys utforskades diagnostiserade sjukdomar, antalet sjukvårdsbesök och kostnaderna för hälso- och sjukvård hos partnern till personen med cancer. Partners till personer som diagnostiserades med cancer mellan 2005 – 2007 deltog (N=10 353) tillsammans med en kontrollgrupp som bestod av ålders och könsmatchade partners till personer utan cancer (N=74 592). I den andra delstudien användes en hermeneutisk ansats för att belysa interaktionsmönstren i familjen när de lever med cancer i en palliativ fas. Analysen baserades på 13 familjeintervjuer. Den tredje delstudien bestod av tre delar: 1) översätta och kulturellt anpassa det engelska instrumentet FSOC-S (Känslan av sammanhang i familjen), 2) undersöka den svenska versionens innehållsvaliditet och 3) utföra en psykometrisk utvärdering. De psykometriska analyserna baserades på frågeformulär från 179 personer med cancer i en palliativ fas och 165 familjemedlemmar. I den fjärde delstudien användes linjära regressionsanalyser för att undersöka associationerna mellan känslan av sammanhang i familjen och hopp, ångest och depressions symptom hos personer med cancer (n=179) och familjemedlemmar (n=165).

Resultat

Studiernas olika karaktär medför att resultaten presenteras studie för studie. Den första delstudiens syfte var att utforska hur cancer påverkar partners hälsa

genom att undersöka partners diagnoser, sjukvårdskontakter och sjukvårdskostnader. Resultatet visade att partners till personer med cancer hade ökade sjukvårdskontakter och sjukvårdskostnader både ett och två år efter cancerdiagnosen. Vilken cancerform personen hade var associerat med i vilken grad partnern hade ökade sjukvårdskontakter och sjukvårdskostnader. Speciellt var det partners till personer med lever-, lung-, colon- och gruppen övriga cancerformer som hade signifikant ökade sjukvårdskontakter och sjukvårdskostnader.

I den andra delstudien, som syftade till att belysa interaktionsmönstren i familjen när de lever med cancer i en palliativ fas, framkom att familjerna anpassade sina interaktionsmönster för att möta den förändrade livssituationen. Tre interrelaterade interaktionsmönster framkom: *maktfördelningen i familjen*, *det hemliga spelet i familjen* och *pendlingen mellan närhet och distans i familjen*. Det framkom att *maktfördelningen i familjen* synliggjordes när personen med cancer gavs ökad makt, och att hans/hennes behov och önskningsar bestämde hur familjen skulle agera den tid de hade kvar tillsammans. Familjemedlemmarna satte sina egna behov och önskemål åt sidan för att främja en så bra tid tillsammans som möjligt. *Det hemliga spelet i familjen* påvisades när hela familjen undvek konflikter och inte pratade om sina tankar och känslor. Hur varje familjemedlem agerade berodde på hur viktig den aktuella situationen var. *Pendlingen mellan närhet och distans* blev synlig speciellt när personens symtom från cancer blev förvärrade. Personen var då tvungen att prioritera vad den skulle använda sin energi till och vem de ville ha nära och vem de ville ha en distans till. Även familjemedlemmarna gjorde dessa prioriteringar om närhet respektive distans. Många familjemedlemmar ville ha en närmare och mer intensiv kontakt med den cancersjuka, speciellt var det märkbart hos de vuxna barnen.

Den tredje delstudiens syfte var att översätta, kulturellt anpassa och utvärdera den svenska versionen av instrumentet S-FSOC-S (känslan av sammanhang i familjen) med fokus på validitet och reliabilitet. Resultatet visade att S-FSOC-S var begreppsmässigt likvärdig med den engelska versionen och lingvistiskt valid med acceptabel validitet och reliabilitet. S-FSOC-S är användbar till att värdera känslan av sammanhang för personer med cancer i palliativ fas och deras familjemedlemmar.

Slutligen var syftet i den fjärde delstudien att undersöka sambandet mellan känsla av sammanhang i familjen och hopp, ångest och depressionssymtom. Resultatet visade signifikanta och oberoende associationer mellan känslan av sammanhang i familjen och hopp, ångest och depressionssymtom. Detta innebär att stark känsla av sammanhang i familjen är associerat med högre grad av hopp och lägre grad av ångest och depressionssymtom för både personer med cancer och deras familjemedlemmar.

Slutsatser och kliniska implikationer

Familjers livssituation påverkas av att leva med cancer både för enskilda familjemedlemmar och familjen som enhet. Partners hälsa blev påverkad av att leva tillsammans med en person med cancer. Cancerformen kan indikera partners risk för försämrad hälsa. För familjer som lever med cancer i palliativ fas förändras deras interaktionsmönster för att uppnå balans och välbefinnande. Dessutom förändrades interaktionsmönstret för att förbättra familjens möjlighet att hantera sin livssituation utan att såra varandra. För att värdera känsla av sammanhang i familjen kan S-FSOC-S användas utifrån personer med cancer i palliativ fas och deras familjemedlemmars perspektiv. Detta kan underlätta för att identifiera familjer med svag känsla av sammanhang i familjen och som kan behöva professionellt stöd för att hantera sin livssituation. Att bättre förstå familjernas komplexa livssituation och de olika utmaningar de ställs inför kan öka kunskapen och underlätta för sjukvården att erbjuda den mest optimala vården för varje familj.

Implikationer för cancervården och den palliativa vården utifrån avhandlingens resultat indikerar att det finns ett behov av ett familjefokus genom hela omvårdnadsprocessen under alla stadier av cancersjukdomen för att främja välbefinnande i familjen. Det är också av vikt att hälso och sjukvårdspersonalen är uppmärksam och har en dialog med familjen om dess risk för ohälsa relaterat till den stressfulla livssituation de befinner sig i. Familjernas interaktionsmönster kan hjälpa hälso och sjukvårdspersonalen att identifiera familjer som har svårare att anpassa sig till sin nya livssituation. Det är vanligt för familjer att uppleva försämrat välbefinnande när de lever med cancer, därför behöver interventioner utvecklas som kan erbjudas till de familjer som behöver professionellt stöd. För att främja familjernas välbefinnande kan det behövas interventioner riktade mot både enskilda familjemedlemmar och familjen som enhet. Hälsostödjande familjesamtal är ett exempel på en intervention riktad

mot familjen som enhet, vilken kan användas under alla cancersjukdomens stadier. S-FSOC-S kan användas för att identifiera familjer med svag känsla av sammanhang och som diskussionsunderlag för att underlätta en implementering av ett familjefokus.

Förslag på fortsatt forskning

För att utveckla den familjefokuserade omvårdnaden för familjer som lever med cancer är vidare forskning önskvärd. Både kvantitativa och kvalitativa studier behövs för att öka kunskapen och fördjupa förståelsen av både enskilda familjemedlemmar och familjen som enhet. Exempelvis finns det ett behov av att undersöka hur familjerna kommunicerar med varandra och hur enskilda familjemedlemmar stödjer och påverkar andra familjemedlemmar. Även utvärderingar av familjefokuserade interventioner behövs för att stärka evidensen av vilken intervention som är bäst för familjer som lever med cancer. Dessutom behövs ytterligare utvärderingar av hur S-FSOC-S kan användas som ett screeninginstrument för att identifiera familjer med risk för försämrat välbefinnande.

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