A support group programme for family members: an intervention during ongoing palliative care
To Life
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Abstract


Family members are central in providing care for patients with life-threatening illness, but they often experience a lack of necessary preparation and knowledge, with a need for information and psychosocial support. The overall aim of this thesis was to investigate participant’s experiences as well as effects of a support group programme for family members of patients with life-threatening illness during ongoing palliative care. Methods: A mixed method design was used. Study I was retrospective descriptive and used a phenomenological method to analyse 10 face-to-face interviews about experiences of participating in the programme. Study II was retrospective descriptive and used qualitative content analysis to analyse 29 telephone interviews about experiences of the programme design. Study III was correlational and used a confirmatory factor analysis to psychometrically evaluate the preparedness for caregiving scale (PCS), caregiver competence scale (CCS) and rewards of caregiving scale (RCS) in 124 family members. Study IV was prospective quasi-experimental and used inferential statistics to investigate effects of the programme, assessing preparedness, competence, rewards, anxiety, depression, hope and health in 125 family members. Results: The main experiences of participation in the programme were; a sense of safety and belonging, confirmation, insight into the gravity of the illness, and a moment of rest. The programme was experienced as covering topics of interest, structured to make participants feel invited by the caring team and using an open approach that fostered a warm atmosphere. The Swedish versions of PCS, CCS and RCS were shown to be valid and reliable. Family members who participated in the programme significantly increased in preparedness, competence and rewards in relation to caregiving. No significant changes were shown for anxiety, depression, hope and health. Clinical implications: The results should provide encouragement in the challenging work to develop and deliverer interventions, with the explicit purpose of supporting family members in palliative care.

Keywords: competence, family members, interventions, palliative care, preparedness, rewards, support groups.

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IV. Henriksson A, Årestedt K, Benzein E, Ternestedt B-M & Andershed B. Effects of a support group programme for family members of patients with life-threatening illness during ongoing palliative care. Accepted for publication in *Palliative Medicine*.

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List of publications


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Populärvetenskaplig sammanfattning

Ett stödprogram för närstående: en intervention under pågående palliativ vård

Bakgrund

Palliativ vård


Närstående i palliativ vård


Interventioner för närstående i palliativ vård

Många studier visar att närstående ofta upplever sig vara otillräckligt förberedda för att hantera vårdarrollen och har behov av information och stöd. Trots det så finns relativt få dokumenterade interventioner för att stödja närstående under pågående palliativ vård. De interventioner som har beskrivits varierar i design där en del är individuellt riktade och andra är i grupp. Genomförandet varierar från personliga möten, telefonsamtal och videotelefonsamtal mellan närstående och sjukvårdspersonal, till broschyrer, och information och konversationsmöjligheter via Internet. Det varierar också när interventionerna har genomförts, hur länge de pågått och vad de har innehållit. Även design för utvärdering varierar och sammantaget
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har det därför hittills varit svårt att få fram evidens om interventionernas betydelse för närståendes upplevelser och förmåga att hantera den vårdande situationen. En nyligen genomförd Cochrane översikt visar dock att det finns evidens för att interventioner som syftat till att stödja närstående under pågående palliativ vård har givit ett känslomässigt stöd samt en hjälp för närstående att hantera sin vårdarroll och också öka deras eget välbefinnande.

**Syfte**

Det övergripande syftet med avhandlingen var att undersöka deltagares erfarenheter samt effekter av ett stödprogram för närstående till personer med livshotande sjukdom under pågående palliativ vård. Avhandlingens specifika syften var att:

I    Undersöka hur närstående till svårt sjuka, döende patienter, upplevde att delta i ett stödprogram och vilken betydelse deltagandet hade för deras liv som närstående.

II   Undersöka upplevelser av en intervention för närstående till patienter med livshotande sjukdom under pågående palliativ vård, avseende innehåll, struktur och förhållningssätt.

III  Att översätta, anpassa och psykometriskt utvärdera; the Preparedness for Caregiving Scale, the Caregiver Competence Scale and the Rewards of Caregiving Scale för användning bland närstående till patienter med livshotande sjukdom i Sverige.

IV  Att undersöka effekter av ett stödprogram för närstående till patienter med livshotande sjukdom under pågående palliativ vård.

**Metod**

En mixed metod design har använts för att studera stödprogrammet. Studierna I och II hade en kvalitativ ansats med en retrospektiv beskrivande design. Studierna III och IV hade en kvantitativ ansats med correlational (III) och prospektiv qvasi-experimentell design (IV).

**Interventionen: ett stödprogram**

Syftet för interventionen var att erbjuda närstående en möjlighet att öka sin förberedelse och kunskap för att vårdas. Interventionen syftade också till att stödja närståendes välbefinnande och minska risken för negativa konsekvenser relaterade till vårdande. Förberedelse och kunskap samt egen be-
hållning i relation till vårdande har funnits vara resurser med kraft att skydda mot negativa konsekvenser och bevara välbefinnande.

Interventionen genomfördes av det team som vårdade patienten, och närstående inbjöds att delta i en stödgrupp som träffades på vårdenheten 6 gånger, en gång i veckan, i 90 minuter. Varje träff hade ett speciellt tema med en inbjuden gäst från det professionella teamet. Teman var; kost (dietist eller sjuksköterska), palliativ vård (läkare), att leva nära någon svårt sjuk (kurator eller psykolog), att hantera vardagen (sjukgymnast och arbetsterapeut), när livet ställs på sin spets (präst) och att vara närstående (gruppledare) Två sjuksköterskor från teamet fungerade som gruppledare och deltog vid varje träff. Programmet startade varje träff med en halvtimmes fri konversation och fika för deltagare och gruppledare innan den professionella gästen anslöt. Stor vikt lades vid ett öppet förhållningssätt, där deltagarnas behov och frågor guidade innehållet i träffarna.

**Studiernas genomförande**

Interventionen genomfördes vid tre vårdenheter. Två av dem var specialiserade palliativa enheter och den tredje var en hematologisk enhet. En fjärde vårdenhet användes som jämförelsegrupp i de kvantitativa studierna. Alla fyra enheter var bemannade dygnet runt, bedrev både hemsjukvård och avdelningsvård, och bestod av multiprofessionella team. Deltagare i alla fyra studierna var närstående till patienter vid någon av de fyra vårdenheterna. Närstående definierades som ”någon som står mig nära” och hade identifierats av patienterna. En majoritet av patienterna (95 %) hade en avancerad cancersjukdom. Patienterna vårdades omväxlande på vårdavdelning och i hemmet och vid tidpunkt för studierna vårdades ca 80 % i hemmet.

I studie I genomfördes öppna intervjuer med 10 närstående och i studie II genomfördes semistrukturerade telefonintervjuer med 29 närstående som deltagit i stödprogrammet. I studie III och studie IV användes enkäter för datainsamling och 125 närstående deltog fördelade i en interventionsgrupp och en jämförelsegrupp. Enkäterna innehöll sex validerade frågeformulär avseende förberedelse och kunskap för att vårda, egen behållning av att vårda, hopp, ångest, depression och egen hälsa. En fenomenologisk analys genomfördes i studie I och i studie II användes en kvalitativ innehållsanalys för att analysera data. I studie III och IV användes beskrivande och analyserande statistik.

**Resultat**

Närstående som deltog i stödprogrammet upplevde en känsla av *samhörighet* då de träffade andra i liknande situation. Det var befriande att få de
andras förståelse och deltagarna delade mycket med varandra. Det var bekräftande att bli inbjuden till stödprogrammet och deltagarna kände sig betydelsefulla och viktiga. Det var också bekräftande att ta del av de andra deltagarnas berättelser och teammedlemmarnas information. Det var tröstan tande att höra att man inte var ensam om sina tankar och känslor. Många av deltagarna tyckte att de fick en ökad insikt om allvaret i sjukdomen och insåg gradvis att deras familjemedlem inte skulle överleva sin sjukdom. Det var svårt och smärtsamt men uppfattades ändå som något bra eftersom det gav en förberedelse för situationen, både mentalt men också praktiskt och i samtal med patienten. Deltagandet i stödgruppen erbjöd en stunds vila för närstående. De uttryckte att de kände sig avslappnade, att de i gruppen fick tid för egen vila och reflektion samtidigt som de blev ”serverade” information och fika. Det var också vilsamt att inte behöva förställa sig och de kunde för en kort stund släppa den fasad de annars bar för att orka hålla ra situationen. Tillsammans resulterade dessa upplevelser i en känsla av trygghet där deltagarna kände sig säkrare i sin vårdande roll.

Stödprogrammet upplevdes positivt av de flesta, och ansågs innehålla viktiga teman med relevans för deras vardag och reflektierande livet som närstående till någon svårt sjuk person. Programmets struktur upplevdes vara inbjudande med möjlighet att skapa relationer både till medlemmarna i vårdteamet och till de andra deltagarna. Det öppna förhållningssättet som tillämpades i grupperna, skapade en varm atmosfär, och inbjöd deltagarna till att dela personliga upplevelser, känslor och tankar. Några förslag till tillägg i programmet var information och diskussion kring hur man pratar med och förhåller sig till barn när någon vuxen är svårt sjuk, samt mer information och samtal kring döendet och döden. Ett ytterligare förslag handlade om samtal kring förändrad sexualitet.

De svenska versionerna av: the Preparedness for Caregiving Scale, Care giver Competence Scale och Rewards of Caregiving Scale, visade sig vara användbara, valida och reliabla för närstående till patienter med livshotande sjukdom. Närstående som deltog i interventionen ökade statistiskt signifikant sin känsla av förberedelse för att vårda, sin kunskap för att värda samt känsla av egen behållning av att vårda. I jämförelsegruppen syntes inga förändringar angående förberedelse, kunskap och egen behållning. Inga statistiska förändringar hittades avseende hopp, ångest, depression och egen hälsa i interventionsgruppen eller i jämförelsegrupp.
Diskussion och sammanfattande reflektioner


Närstående med högre känsla av förberedelse och kunskap för att vårdar har visat sig ha mindre risk för bl.a. oro, ångest, depression och större möjligheter till välbefinnande trots den svåra livssituationen. Närstående som deltagit i stödgruppen upplevde att deras situation underlättades tack vare deras ökade förberedelse och kunskap. De upplevde sig vara mer trygga i den vårdande rollen och kapabla att möta patientens behov på ett bättre och säkrare sätt än innan. När man som närstående känner sig mer förberedd och mer kunnig så ökar troligen också känslan av egen behållning av vårdandet. Det ger en känsla av att kunna, och att veta, att det man gör för patienten är rätt och bra.

Det finns studier kring närståendes förberedelse för patientens död. Denna fråga studerades inte explicit i den här avhandlingen men i intervjunerna med närstående framkom att deltagandet i stödprogrammet aktualiserade tankar kring döden. Flera sa att de långsamt började förbereda sig för att patienten inte skulle överleva och att de mentalt gjorde sig redo för den förlusten. Det finns studier som visar att närstående som trots att de utfört avancerad vård och gett stöd i stor omfattning inte känt sig förberedda för patientens död. Dessa närstående kan ha större risk att drabbas av tex ångest, depression och mer komplicerad sorgbearbetning. Öppen och fri konversation tillsammans med tillförlitlig information från professionella vårdgivare kring döende och död har i studier visat sig vara ett bra sätt för närstående att ha en möjlighet att förbereda sig för patientens död.

I palliativ vård har stöd till närstående alltid betonats, dock har det funnits lite guddom i hur stödet kan ges. Det finns flera avgörande frågor när det gäller arbetet med att utveckla interventioner för närstående. Den första frågan är, när interventionen ska erbjudas. I avhandlingen framkom att en del närstående tyckte att de fick ta del av interventionen för sent i patientens sjukdomsskede och några tyckte däremot att det var för tidigt. Utifrån befintlig litteratur så kan interventioner som erbjuds i rätt tid medför-
ling, genomföra och utvärdera av en intervention. En intervention bör också baseras på lämplig teoretisk grund.

Resultaten i avhandlingen visar att det är möjligt att genomföra interventioner i gruppformat för närstående under pågående palliativ vård och att de kan resultera i betydelsefulla positiva upplevelser hos deltagarna. Den här avhandlingen kanske kan stimulera och vara en guide i det utmanande arbetet bestående av utveckling, genomförande och utvärdering av stödinterventioner för närstående under pågående palliativ vård.
Introduction

Almost 18 years ago, as a newly registered nurse, I was led by coincidence to work extra hours at a specialist palliative care unit. Following the recent birth of my first child, questions concerning life, death, and family had become very important to me. I was immediately fascinated by the approach used in palliative care. The patient and their family members are seen as a unit, and the goal is to improve the quality of life of both patient and family. My work as a nurse was influenced and enriched by this approach. When caring for the patients, I also got to know their family members and I came to understand the complexity of being a family member of a person with life-threatening illness. Most family members that I met willingly took on a caring role, and for many, life in their new situation was centred around the illness. It was obvious what a substantial effort they made, and it became clear to me that family members had a double role in which they provided care and support but were also in need of support themselves. Many expressed feelings of loneliness, as if they were struggling alone. They went through things in life that were difficult to talk to others about, and that were difficult for others to understand. They often had questions and worries that could not be expressed to the patient, other family members, or friends. As a nurse I heard many of these thoughts and questions, and I felt invited to share their worries. In this context, concerns and questions arose in my mind about how to best support family members in their challenging situation. These questions guided me into my research studies. Over the past four years, I have studied a support group programme in which family members were invited to meet with others in similar situations, to obtain information and to discuss matters with health professionals. I have investigated both the experiences of the family members and the potential effects of the programme. It seems unreal, but I have actually now finished my thesis. This process produced many answers, but also raised many new questions!
Background
This thesis describes an investigation of a support group programme aimed at supporting family members of patients with life-threatening illness. The point of departure for the studies was the unique and stressful life situations of such family members. The story of Anna, one of the study participants, is summarised below in order to provide an example of the context in which the studies were performed.

Anna is 58 years old. She has been married to Carl for 30 years, and they have three children. Their children are now adults; one of them is studying abroad and the other two are both married and have children. Anna and Carl live together in a large house. Anna is a lawyer, and has always loved her work; she has never minded the long hours that come with the job. She has a number of good friends, with whom she goes for coffee, works out at the gym, and sometimes goes dancing at weekends. Carl, who used to work in construction during the day, prefers to stay more at home. Carl is a very handy man, and throughout their marriage Anna has relied on him both in practical and emotional concerns. Since Anna is very active and social, she has sometimes thought Carl was a little boring, and has had occasional doubts about their marriage. However, he has really been there for her in a loving way. She used to describe him as her “rock”. Today, both their lives are changed. Carl is severely ill with cancer, and Anna helps him with almost everything in their daily life. According to Anna, Carl has aged 20 years in the last 2 months. For some weeks now, Anna has not been able to work, because she wants to stay with Carl and give him the care and the support he needs. She no longer sees much of her friends, since she is afraid to leave Carl on his own; she does not want to take the risk that he will need her when she is away. She is afraid that he will try to get out of bed by himself and fall and get hurt. Maybe he will be in pain, or need to go to the toilet. Carl often says to Anna that he feels safe when she is around, which makes her happy. Being with and caring for Carl makes her feel good inside. However, in all this, Anna feels lonely; she is sad and she is afraid of losing her husband, her companion and rock in life. She is always tired because she can never relax and she has difficulties sleeping. She misses her work and friends, and she feels tied to the home. She cannot tell anyone about these feelings; she is ashamed of even thinking them. This makes her feel lonely. Anna really wants to be there for Carl and to do her best, but she often feels insecure and anxious. However, she is happy that he
lets her care for him. She puts all her efforts into coping with this new life situation in which she takes full responsibility for caring for Carl.

Palliative care

Anna’s story exemplifies the complexity of being a family member of a patient with life-threatening illness. Of course there is wide variation between individuals and families, but the situation of Anna and Carl typifies the kind of needs we often see in palliative care.

Palliative care is defined by the World Health Organisation (WHO) \(^1\) “as an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual/existential”. The definition stresses that palliative care offers a support system to help the family cope during the patient’s illness and in their own bereavement. A team approach is used to address the needs of patients and their families.

The palliative period starts when a disease is diagnosed as incurable and palliative care is prescribed. Palliative care is often divided into an early and a late palliative phase. The early phase can last for several months or even years, and the purpose is to prolong life and provide a high quality of life with good symptom control. The late palliative phase begins when the disease advances and death is expected within a few weeks or days. The aim in this phase is to provide high quality symptom control, to relieve stress, and to optimise wellbeing and comfort. \(^2\)

The European Association of Palliative Care (EAPC) outlines three levels of palliative care. The first level should be used in non-specialist settings which occasionally treat palliative care patients. The second level is general palliative care which should be provided by health care professionals who are more frequently involved in palliative care, but do not provide this type of care as a main focus. The third level is supplied by specialist palliative care services whose main activity is the provision of palliative care. \(^3\) The context for this thesis is specialist palliative care, with a majority of patients in a late palliative phase with complex care and support needs. These needs may include symptom management, emotional and spiritual support, assistance with personal and instrumental care, and transportation, as well as the monitoring of, assessment of, and help with communication with health professionals about disease progression and palliative treatment. \(^4\)

Many patients rely on their family members to manage and supply these needs.
Family members in palliative care

Health care systems in many countries are moving towards outpatient care in which family members are central in providing care for patients with life-threatening illness.5,6 Family members and friends often have a central role in providing care, together with health professionals, regardless of whether the patient is at home or in a formal healthcare setting.4 Family members often undertake a caregiving role; in the scientific literature, these family members are called family caregivers, informal caregivers, caregivers, or carers. They may or may not recognise themselves as carers or family caregivers, but nevertheless will often be involved in providing care and support. They generally provide unpaid physical, practical, and/or emotional care and support, though in some countries they may be in receipt of financial benefits. They may or may not have informal training and qualifications in caring in general, although many will develop expertise in caring for the patient.7 In this thesis, the terms “family members” and “family caregivers” will be used interchangeably. The term “patient” will be used throughout for the sake of clarity and consistency.

Many studies have explored the situation-specific needs, concerns, and experiences of family caregivers, which have resulted in a voluminous literature on caregiving. The caregiving experience has been described as a natural thing to do, something that is done partly out of love but also out of feelings of obligation and responsibility.8 Family members sometimes feel expectations from the patient and the health professionals to become a family caregiver, which can lead to them taking on the role with feelings of doubt, ambivalence, and anxiety.9 Being a family member of someone with life-threatening illness is a new situation for most people, and many feel insufficiently prepared for the caregiving role.9,10 Some of the tasks that family members have to manage and control were previously undertaken by specialists.11 The responsibilities of care can range from simply providing companionship and undertaking household tasks, through assisting with personal care and transport, to performing complex physical and medical tasks as well as patient advocacy, decision making, emotional support, and coordination of care.12-17 The amount and type of care is not generally static, and may change and develop throughout the disease trajectory.7 Historically and transculturally, family caregivers have most likely always played a role in care; however, the level of technical, psychological, and physical support demanded of family caregivers today is often unprecedented.18-20 The general caregiving literature suggests that the caregiving role may be fulfilled by a number of the patient’s family members working together to provide care.21 In practice, what usually happens is that one person, usually co-resident with the patient, takes the predomi-
Many family members describe mixed emotions regarding their caregiving role, and highlight both positive and negative aspects. The caring experience carries the potential for a deepened sense of meaning, greater connection, and accompanying positive affect. Some studies have described how family members experience feelings of satisfaction, thankfulness, and pleasure. Caring can be a way to demonstrate love and to repay the patient for that which they have previously given. However, being a caregiver may also involve considerable physical, emotional, and social challenges and the situation is often arduous and exhausting. Many caregivers exhibit not only psychological distress but also physical symptoms. The negative consequences described in the literature include anxiety and depression, uncertainty, fatigue, sleeplessness, loneliness and social isolation, and general deterioration in health. Willingness to care may play an important role in family caregiving. It could be that family members who do not experience a real choice may be at greater risk for stress, both during and after the caregiving period.

Since the context for this thesis is specialised palliative care, it is important to stress the uniqueness of the experience of being a family member of a person with life-threatening illness approaching the end of life. These family members must face the emotional challenges associated with loss and approaching death. Studies show that family members are more likely to be distressed when patients are in more advanced stages of illness and have more symptoms, greater loss of physical function, and more complex care needs. Furthermore, as the physical condition of the patient worsens, greater demands are made on family members. Studies have shown that as the disease of the patient progresses towards death, family members experience a worsening of outcomes such as anxiety/depression, quality of life, and burden. This is confirmed by a recent review which found that the mutuality between the patient’s physical and emotional concerns and the family caregiver’s response is consistent across studies and striking in scale. The authors of the review concluded that family members in palliative care are at increased risk for physical and mental morbidity, as a direct consequence of assuming the caregiver role. They also underscored the considerable contributions made by family caregivers and the responsibility they must shoulder, and argued that family caregivers represent a sizable part of the population who support their families often at the expense of their own health and wellbeing. Several studies have shown that family members in palliative care report a lack of the necessary preparation, knowledge, and ability to handle the caregiver role, with a consequent
need for information and psychosocial support.\textsuperscript{10,20,38-42} Andershed described this as a metaphor; family members who did not feel informed, seen or acknowledged by the health professionals felt like grouping around in the dark when they tried to support the patient.\textsuperscript{43}

\textbf{Interventions for family members during ongoing palliative care}

Although there is extensive documentation of the unmet needs among family members, several literature reviews report that there are a limited number of interventions addressing family members in palliative care.\textsuperscript{44-48} Addressing the needs of these family members is not straightforward in any way. Their needs may be broad ranging, and may also change during the period of caregiving. This complexity may go some way towards explaining why support for family members is less developed than other aspects of palliative care services. Family members may also not recognise their own needs, or may avoid seeking support in an attempt to avoid redirecting resources away from the patient.\textsuperscript{49,50} A recent Cochrane review on randomised controlled trials of interventions for supporting caregivers of patients in the terminal phase of disease identified 11 such interventions.\textsuperscript{4} Nine interventions were delivered directly to the caregiver;\textsuperscript{51-59} seven of these provided support in the caring role, while one involved a family life review and one grief therapy. However, the literature also contains studies of interventions aiming to support family members that are not randomised controlled trials. From the literature it becomes clear that interventions for family members during ongoing palliative care vary a great deal concerning intervention conceptualisation, aim, design, and delivery. There is also a variation in evaluation design and in outcome measures (Table 1).

Individually targeted support and education interventions such as massage, personal home visits, and phone or videophone communication with health professionals have been found to decrease feelings of burden, physical pain, and sleeping disorders\textsuperscript{56,60} and to improve health, quality of life, and wellbeing\textsuperscript{53,61,62} among family members. In addition, family members reported a significantly more positive caregiver experience after taking part in an individual targeted intervention.\textsuperscript{57} Interventions have also been delivered in group format during ongoing palliative care, and the relatively few existing studies indicate that this could be a valuable approach.\textsuperscript{63-65} According to qualitative findings, the opportunity to meet others in similar life situations, identifying with others and validating one’s feelings, discussing matters with professionals, and providing mutual support seem to be especially appreciated.\textsuperscript{63,64,66} Quantitative results reveal increased levels of preparedness, competence, and rewards after participation in a support group programme.\textsuperscript{65,67} Group interventions have the advantage of provid-
ing opportunities for family members to interact and develop networks with others who are undergoing similar experiences.\textsuperscript{68,69} Another advantage of group interventions versus individual targeted interventions is their relatively low financial costs for health professionals, as many family members can be supported at once.\textsuperscript{68} However it can be difficult for family members to attend group programmes because of caring responsibilities, other personal or family obligations, lack of time, or transport problems.\textsuperscript{70,71} It is also important to recognise that support groups may not be appropriate for all family members, and vulnerable persons in particular may have their needs best met in individual targeted intervention.\textsuperscript{72} However, there is no consensus as to what sort of intervention best eases the situation of family members, and the optimal design of interventions to meet family members’ needs is still unknown.\textsuperscript{53} It is also generally difficult to identify transferable principles and understand the reasons underlying the success or failure of given interventions.\textsuperscript{25}

We do not currently know how or what is the best way to support family members in palliative care, but findings from research emphasise the importance of support in general. Support in the form of trusting relationships, support networks, and sharing caregiving tasks has been found to contribute to feelings of security,\textsuperscript{73-75} hope,\textsuperscript{76} reassurance,\textsuperscript{77} a sense of togetherness with others, trust,\textsuperscript{77,78} and manageability.\textsuperscript{78} Support can also alleviate anxiety, stress, and uncertainty,\textsuperscript{79-81} as well as feelings of abandonment or isolation.\textsuperscript{78,82,83} While support in general seems to affect the experience of the caregiving period, according to the aforementioned Cochrane review there is limited evidence for the effectiveness of interventions for family members during ongoing palliative care. The review concludes that interventions that directly support the family members help them to cope emotionally, and may help them to cope with their role in caring and also improve their quality of life. Hence there is evidence that supportive interventions may help reduce psychological distress among caregivers. There is also low quality evidence that in the short term these interventions may marginally improve coping skills and quality of life.\textsuperscript{4}
<table>
<thead>
<tr>
<th>Author</th>
<th>Intervention</th>
<th>Study design</th>
<th>n</th>
<th>Measures</th>
<th>Design for evaluation</th>
<th>Results</th>
</tr>
</thead>
</table>
| MacDo-  
|  
| nald, 1998  
|  
| 60            | Massage for 1.5 hour, once a week for 3 weeks                               | Quasi-experimental     | 13  | -Non validated instruments Emotional and physical stress, physical pain and sleeplessness | Baseline and follow up Feedback                         | 85% rated decreased emotional stress, 77% rated decreased physical pain, 54% rated less sleeping problems |
| Gagnon et  
|  
| al., 2002  
|  
| 84           | Psycho-educational focusing on delirium delivered face to face by bedside nurse including a brochure | Quasi-experimental     | 124 | -Non validated instruments assessing delirium knowledge, perceived competence and attitude towards delirium | Baseline and follow up                                      | Only a modest effect was found                                      |
| Witkowski  
|  
| et al., 2004  
|  
| 63          | A support group programme, 5 sessions with specific themes                  | Descriptive phenomenografic design | 39  | -Perceptions of the programme -Experiences of participation              | Evaluative questionnaire Interviews after participation | The evaluation showed an overall satisfaction with the programme     |
| Milberg et  
|  
| al., 2005  
<p>|<br />
| 64          | A support group programme. Six sessions 1,5 hour, once a week               | Descriptive design     | 19  | -Experiences of the support group programme                              | Evaluative questionnaire Focus groups interviews          | Experiences of increased perception of support and knowledge        |</p>
<table>
<thead>
<tr>
<th>Author</th>
<th>Intervention</th>
<th>Study design</th>
<th>n</th>
<th>Measures</th>
<th>Design for evaluation</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hudson et al., 2005</td>
<td>A psycho-educational intervention. Two home visits and one phone call from intervention nurse. A caregiver guidebook and audi-tape</td>
<td>Randomized controlled trial</td>
<td>106</td>
<td>-The preparedness for caregiving scale (PCS)</td>
<td>Baseline and follow up after participation (5 weeks ) and 8 weeks after patient death</td>
<td>Significant increases in rewards of caregiving</td>
</tr>
<tr>
<td>Low et al., 2005</td>
<td>Family members were offered respite when patients are invited to day-care center</td>
<td>Qualitative evaluation design</td>
<td>12</td>
<td>-Evaluation of the day-care center. -Experiences of the impact of quality of life for family members</td>
<td>3 focus group interviews</td>
<td>Respite was a benefit for family members. Day care staff was also seen as a resource to turn to with questions and worries</td>
</tr>
<tr>
<td>McMillan et al., 2006</td>
<td>COPE-problem based coping. Creativity, optimism, planning and expert information 9 days, 3 home visits by intervention nurse, phone calls, written information</td>
<td>Quasi-experimental design with three research arms -Standard care -Standard care and friendly visit -Standard care and intervention</td>
<td>329</td>
<td>-Caregiver quality of life (CQOL-C) -The Memorial symptom assessment scale (MSAS) -General caregiver mastery -Caregiver demands scale (CDS)</td>
<td>Baseline, Follow up day 16 Follow up day 30</td>
<td>Intervention group increased quality of life, decreased stress and burden</td>
</tr>
<tr>
<td>Author</td>
<td>Intervention</td>
<td>Study design</td>
<td>n</td>
<td>Measures</td>
<td>Design for evaluation</td>
<td>Results</td>
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<tr>
<td>Carter, 2006</td>
<td>A brief behavioural sleep intervention</td>
<td>Randomized controlled trial</td>
<td>30</td>
<td>-The Pittsburgh sleep quality index (PSQI)</td>
<td>Baseline, follow up week 2, 3, 4, 5, months 2, 3, 4</td>
<td>Improvement in sleep quality, depressive symptoms and quality of life</td>
</tr>
<tr>
<td>Walsh et al., 2007</td>
<td>Six individual meetings with an educated canceller to support the needs of the family member</td>
<td>Randomized controlled trial with two research arms</td>
<td>271</td>
<td>-General health questionnaire (GHQ-28)</td>
<td>Measures 4, 9, 12 weeks after randomisation</td>
<td>No significant statistical changes. The interviews showed a value of emotional support</td>
</tr>
<tr>
<td>Hudson et al., 2008</td>
<td>A psycho-educational group programme in 3 sessions</td>
<td>Quasi-experimental design</td>
<td>74</td>
<td>-The Preparedness for caregiving scale. (PCS)</td>
<td>Baseline, follow up immediately after programme and 2 weeks later</td>
<td>Increases in preparedness, competence and rewards. The programme was shown to be feasible, acceptable and effective</td>
</tr>
<tr>
<td>Demiris et al., 2007</td>
<td>Videophone communication in home care</td>
<td>Quasi-experimental design</td>
<td>12</td>
<td>-The state trait anxiety inventory (STAI).</td>
<td>Baseline and continuous measures every two weeks until the death of the patient. Interviews</td>
<td>Decreased anxiety. A feeling of security. Positive experiences of the intervention</td>
</tr>
<tr>
<td>Author</td>
<td>Intervention</td>
<td>Study design</td>
<td>n</td>
<td>Measures</td>
<td>Design for evaluation</td>
<td>Results</td>
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</tr>
<tr>
<td>Parsons &amp; Anderson, 2009</td>
<td>Afternoon tea on a palliative care unit</td>
<td>Ethnographic design</td>
<td>8</td>
<td>-Experiences of the intervention</td>
<td>Interviews Observations Field notes</td>
<td>The afternoon tea was a welcomed distraction of caring and comfort</td>
</tr>
<tr>
<td>Cronfalk et al., 2009</td>
<td>Soft tissue massage, 25 minutes, 9 occasions</td>
<td>Explorative design</td>
<td>19</td>
<td>-Experiences of soft tissue massage as support</td>
<td>Interviews 1-2 weeks after intervention</td>
<td>A sense of inner power, physical strength and existential wellbeing in daily life</td>
</tr>
<tr>
<td>Demiris et al., 2010</td>
<td>A standardized problem-solving intervention. 3 visits by a research team member. The agenda was based on problems identified by the caregiver</td>
<td>Quasi-experimental design Qualitative evaluation</td>
<td>29</td>
<td>-Quality of life -Anxiety</td>
<td>Baseline and follow up</td>
<td>Decreased levels of anxiety. Higher quality of life. Improved problem solving skills. High levels of satisfaction with the intervention</td>
</tr>
<tr>
<td>Greene et al., 2011</td>
<td>A community network facilitator assessed caregiver needs and helped mobilize the caregivers own support network. 3 planned visits at 4 weekly intervals</td>
<td>Quasi-experimental design</td>
<td>66</td>
<td>-Duke social support index -The catholic health care coalition family caregiver questionnaire -AMA carer self check</td>
<td>Baseline and follow up at 4 and 8 weeks</td>
<td>Improvement in fatigue, perceived support from others; decreased resentment in the role; greater confidence in ability to find resources and support. Decreases in manageability in care</td>
</tr>
</tbody>
</table>

Note: Search strategy in Pubmed and Cinahl; palliative care and intervention and family members and/or family carers and/or family caregivers and/or carers and/or next of kin.
Theoretical standpoints

The thesis takes its stance in a humanistic view of life, in which people are seen as unique beings who are in the midst of becoming and whose wholeness is made manifest in thoughts, feelings, and behaviours. In this view, people are becoming, growing, self-reflecting, and seeking to connect with others; and they both shape and are shaped by the environment in which they exist. The participants in this thesis were family members of people with life-threatening illness. They were in a stressful, disrupted life situation, going through transitions, caring for someone close to them, and both giving and in need of support. The concepts of transition, caring, and support are the theoretical standpoints of this thesis. These interrelated concepts can be helpful in deepening the understanding and interpretation of the results.

Transition

According to Chick and Meleis, transition can be understood as a passage from one life phase, condition, or status to another. Transitions are complex processes and include changes in identities, roles, relationships, abilities, and patterns of behaviour. There are several important factors influencing transition, including meaning, preparation, level of knowledge, expectation, uncertainty, and emotional and physical wellbeing. Meaning refers to the subjective appraisal of a transition and its likely effect on life. Preparation facilitates the transition experience, and inherently related to this is knowledge about what to expect during a transition and what strategies may be helpful in managing it. The stress that is often associated with transition may be somewhat alleviated by knowing what to expect.

Penrod et al. describe a concrete theoretical model of caregiving through the end of life. The caregiving period is described as four phases punctuated by three key transitions. The phases of the caregiving period are patterned transitions in the illness experience of the patient. The first phase, “sensing a disruption”, is when a health problem is first recognised and then diagnosed as a life-threatening illness. The transition is abrupt; the old way of life is gone, and the second phase of the caregiving period, “challenging normal”, begins. In this phase, the patient’s life is focused on new treatments and frequent health care appointments. Family members take on an assistance role while striving to retain some semblance of normal life. This phase takes a dramatic turn when the patient is moved to palliative treatment and a transition occurs to the third phase, “building a new normal”. This phase includes active caregiving, and family members
focus on establishing a pattern of caring that is often perceived to be a 24-hour responsibility. The final transition takes place when the patient dies and family members enter the last phase, “reinventing normal”, in which they grieve their loss and begin to assemble a new pattern of normality. 94

Caring

The caregiving model 94 described above demonstrates how family members of a dying person transition through phases in their lives patterned by the illness of someone close to them. Each of the phases is characterized by different levels and amounts of caring. The shifting phases of caregiving cannot be halted, as the disease does not “stand still”, and family members find themselves responding to a changing landscape of care. 94 The family members whose experiences contributed to the development of the model probably did what most people would have done in the same situation. Caring is in fact the oldest and most elementary sort of human behaviour; it has been, and still is, necessary for human health and survival. Mayeroff 95 reflects philosophically on caring as something we do, human to human, that could mean helping each other to grow and actualize ourselves. Caring is like a relationship that develops with changes in the person who cares and the person who is cared for. Mayeroff describes a number of major ingredients in caring: knowledge, patience, honesty, trust, humility, hope, and courage. According to Mayeroff we need knowledge to care; if we understand the needs of the one we care for, this could facilitate our ability to respond to them. By trying to be patient and using our knowledge we may enable the other person to grow in their own way and in their own time. Patience is not waiting passively for something to happen, but involves participating with the other person and trying to share and give of ourselves. If we try to use our honesty in caring, we may truly see the other person as they are, and we may also see ourselves as we are. With trust and humility we can learn from each other. Caring involves both hope and courage; we hope that the other person will grow through our caring, and we may also need courage to stand by them in trying circumstances. Courage is also present in entering what for most people is unknown situations, that of caring for someone close. However, to have courage is not to be blind; it is to be informed by insight from past experience and to be open and sensitive to the present. When we care for another person we may actualize ourselves and we may also grow, because our interest is focused on the other. Mayeroff also speaks about the ability to care; if we are to care for another person, we need to be able to cope with it. In caring we often commit ourselves to the other person, in a way, and we may hold ourselves out as someone who can be depended on. However, since caring
can sometimes be stressful and difficult, we may not always be able to keep the promises we have made to ourselves or others. This may result in feelings of guilt. 95

Kirsten Swanson’s theory of caring ties in with Mayeroff’s philosophical discussion, and includes five caring processes: knowing, being with, doing for, maintaining belief, and enabling. Knowing is striving to understand the other person’s experience of the situation. Being with is understood as being emotionally present for the other person and being willing to share feelings. Doing for includes those actions that are helpful, protective, and/or increase comfort; actions that the person being cared for would normally perform themselves if it were possible. Maintaining belief involves sustaining one’s faith in the capacity of others to get through events or transitions and face a future with meaning. It also includes maintaining a hope-filled attitude and standing by the person who is being cared for. Finally, Swanson talks about the concept of enabling as facilitating the other person’s passage through life transitions and unfamiliar events. This implies trusting and supporting the individual to be resourceful with the capacity to grow, heal, and or practice self care, which could also be related to caring for others. This involves providing information, explanations, and emotional support in the form of validating the person’s feelings. 96,97 Swanson’s theory of caring was originally developed in a professional nursing context, but this context has features in common with other caring relationships, and the theory seems to be applicable to family members caring for a severely ill person. 17,98

Support

Even if caring is an elementary human behaviour, this need not mean that it always comes naturally or that it is easy in any way. We know that caring for someone with life-threatening illness can be a real challenge, and is often associated with negative consequences. Many family members in this situation are in need of support, but they are also expected (sometimes by others, sometimes by themselves) to support the person they care for. It is not easy to define what constitutes support and its fundamental nature in a way that is generally accepted, 99 and the meaning of the concept may vary depending on discipline and context. 100 The concept of support is used repeatedly within nursing and palliative care, particularly in relation to family caring and family caregivers, 100 and it actually seems to be closely related to the way ideas of caring. 101 In the nursing research literature, the terms “support”, “social support”, “professional support”, “proactive support”, and “psychosocial support” are often used interchangeably. In this thesis, the most appropriate terms seem to be “social support” and
“professional support”, since the term “support” is often used to describe that which occurs between family caregivers and the person being cared for as well as that which occurs between professional caregivers and family caregivers. ¹⁰²,¹⁰³

**Social support**

Social support is a complex, dynamic, and fluid concept that has been studied extensively both from research and theoretical perspectives. The unique feature of social support is that the support must be provided by someone who has a personal relationship with the recipient, and therefore social support is often defined in relation to personal relationships. ¹⁰⁴ Cobb, ¹⁰⁵ for example, stated that social support is information which leads a person to believe that they are cared for and loved, that they are esteemed and valued, and/or that they belong to a network of communication and mutual obligation. According to Hoboll & Stokes, ¹⁰⁶ social support comprises those interactions or relationships that provide individuals with assistance or a feeling of attachment to a person or a group that is perceived as caring or loving. However, many theoreticians have argued that the theoretical definitions of social support are too restrictive and inadequate, because the concept is multifaceted. A conceptual analysis by Langford et al. ¹⁰⁷ suggested that four of the most frequently used defining attributes of social support are emotional, instrumental, informational, and appraisal support. Emotional support involves the provision of caring, empathy, love, and trust. ¹⁰⁸,¹⁰⁹ Instrumental support involves the provision of caring, empathy, love, and trust. ¹⁰⁸,¹⁰⁹ Informational support is information provided to another person during a time of stress, aimed at helping them to solve problems. ¹⁰⁸,¹⁰⁹ Appraisal support involves the communication of information which is relevant to self-evaluation rather than problem-solving. ¹⁰⁹ Each of these four defining attributes of social support is helpful and protective to the person receiving the support, and each of them is assumed to result in health and well-being. ¹⁰⁷ Langford et al. ¹⁰⁷ also suggest that social network, social embeddedness, and social climate are inherent antecedents of social support. Social network is the structure of an interactive process, social climate is the personality of an environment, and social embeddedness is the connectedness that a person has to significant others within their social network. ¹¹¹ The consequences of social support are personal competence, health maintenance behaviours, effective coping behaviours, perceived control, positive affect, sense of stability, recognition of self-worth, decreased anxiety and depression, and psychological well-being. These antecedents, defining attributes, and consequences can be integrated into the theoretical foundations of social support. ¹⁰⁷
Professional support

Professional support differs from social support in that it does not require reciprocity to the same extent as social support, and in that the provider of the support is a professional. Relationships in professional support are based on certain role expectations. The support requested and provided should be within the domains of the professional role. Professional support is not necessarily based on mutual expectations, but rather on expectations inherent in the professional role. This thesis uses the definition of professional support given by Stoltz et al., since this definition focuses particularly on support for family carers. Here, support is seen as two intersecting dimensions that are inevitably and dialectically integrated. The first is a tangible, concrete, and general impersonal dimension which is concerned with increasing the family caregiver’s capacity to care. The other dimension is intangible, abstract, and highly individual; it involves the family carer unburdening their mind to a dedicated other. These two dimensions are merged into the following definition: “Support entails the provision of general tangibles such as information, education, economic aid, goods and external service. These are prerequisites for facilitating the family carer’s competence and/or capacity in care. Moreover, it entails necessary qualities such as individualization, adaptability, lastingness, room for verbalizing emotions as well as an idea of reciprocal, symmetrical exchange between involved parties.”
Rationale of the thesis

Health care systems in many countries are moving towards a model of outpatient care in which family members are central in providing care for patients with life-threatening illness. Family members often feel insufficiently prepared for this new situation in life, which includes complex physical and medical tasks as well as patient advocacy, decision making, emotional support, and coordination of care. It must be recognised that in addition to this, these family members must also deal with their own feelings, thoughts, worries, and grief. They are going through complex transitions as their lives have often changed considerably as a consequence of the illness. It is well known in the literature that many of them put their own lives on hold and live exclusively for the patient. Several studies have shown that family members in palliative care report a lack of the necessary preparation, knowledge, and ability to handle the caregiver role, with a consequent need for information and psychosocial support. Reviews of the literature reveal a limited number of studies on interventions for family members of patients with life-threatening illness during ongoing palliative care. The results of these studies emphasise the importance of support, but there is no consensus as to what sort of intervention best eases the situation of family members, and the optimal design of interventions to meet family members’ needs is still unknown. Addressing this gap should be a priority, and therefore more studies investigating interventions aiming to support family members during ongoing palliative care, are needed.
Overall aim

The overall aim of this thesis was to investigate participant experiences as well as effects of a support group programme for family members of patients with life-threatening illness during ongoing palliative care. The overall aim also included to evaluate appropriate instruments and use them to investigate effects of the support group programme.

Specific aims

The thesis includes four specific aims:

I  To describe how relatives of terminally ill and dying people experienced being participants in the support group programme and what impact the support group had on their lives in the context of being a relative to a person in the last palliative phase.

II To describe family members’ experiences about the content, structure, and approach of a potential intervention including a support group program for family members of persons with life-threatening illness during ongoing palliative care.

III To translate, adapt and psychometrically evaluate the Preparedness for Caregiving Scale, the Caregiver Competence Scale and the Rewards of Caregiving Scale for use in a Swedish sample of family members of patients with life-threatening illness.

IV To investigate effects of a support group programme for family members of patients with life-threatening illness during ongoing palliative care.
Method

Design
A mixed method design was used to study the support group programme (table 2). Studies I, II had a qualitative approach with retrospective descriptive design. Studies III and IV took a quantitative approach with a correlational design (III) and a prospective quasi-experimental design (IV). 112

Table 2. An overview of the studies in the thesis

<table>
<thead>
<tr>
<th>Study</th>
<th>I</th>
<th>II</th>
<th>III</th>
<th>IV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Design</td>
<td>Retrospective descriptive</td>
<td>Retrospective descriptive</td>
<td>Correlational</td>
<td>Prospective quasi-experimental</td>
</tr>
<tr>
<td>Participants</td>
<td>n= 10 Family members</td>
<td>n= 29 Family members</td>
<td>n=124 Family members</td>
<td>n=125 Family members</td>
</tr>
<tr>
<td>Data collection</td>
<td>Face-to-face interviews</td>
<td>Telephone interviews</td>
<td>Self-rated instruments</td>
<td>Self-rated instruments</td>
</tr>
<tr>
<td>Data analysis</td>
<td>Phenomenology</td>
<td>Qualitative content analysis</td>
<td>Descriptive and inferential statistics</td>
<td>Descriptive and inferential statistics</td>
</tr>
</tbody>
</table>

The intervention: a support group programme

Aim and conceptualisation of the intervention
The aim of the intervention was to offer family members an opportunity to increase their feelings of preparedness, competence, and rewards in relation to caregiving. Overall, the intervention aimed to support the family members’ wellbeing and decrease the negative consequences related to caregiving. The intervention was influenced by methodological and empirical work on support for family members, which has confirmed that preparedness, competence, and rewards are concepts with the power to support...
Feelings of being prepared, competent, and/or rewarded have been described as resources which influence the way family members handle the caregiving situation. The support group programme (Table 3) was based on a comprehensive inventory of the relevant scientific literature, several years of experience from palliative care staff (elicited via informal conversations), and an inventory of the needs of family members at one palliative care unit. The programme had both a supportive and an educational component, starting off with half an hour of free conversation between the participants followed by a professional guest presenting a specific topic.

**Intervention delivery**

Family members were invited to meet with others in similar situations, to obtain information, and to discuss matters with professionals. The programme was delivered during ongoing palliative care by the multi-professional team caring for the patients, and took place at the care unit. The group met once a week for 90 minutes. The programme included 6 sessions, each of which had a different topic presented by a professional guest from the caring team. Two nurses from the team acted as group leaders and participated in each meeting. The nurses initiated and coordinated the programme and also encouraged the group in conversations during the meetings. One important aspect of the programme was that these nurses welcomed the participants each time they arrived at the ward, to make them feel comfortable and taken care of. The nurses had several meetings with one of the researchers during the study period, including formal and informal conversations about the aim, structure, and delivery, in order to secure the coherence of the programme.

Much of the emphasis in the programme was on the family members and their wellbeing, and the ability to handle the illness situation. An important feature of the meetings was open-mindedness concerning the family members’ needs. Although the professional guests had prepared in advance their ideas on how to present and what to include in their specific topic, they were encouraged to be open to the participants’ questions and wishes about what to discuss.

The programme was structured to start with half an hour of free conversation where the participants had a chance to get to know each other and to talk about anything they wished; sometimes this might be something that had happened at home during the week in relation to the patient, or something else concerning their present life situation, but it could also be small talk about the weather, shopping, or other things. During this first half hour, coffee, tea, and sandwiches were served. The programme took
place at 5pm in order to ensure that those who were employed were also given a chance to participate.

The researchers in the studies were not involved in the delivery of the support group programme.
Table 3. Structure and content of the support group programme

<table>
<thead>
<tr>
<th>Meeting 1</th>
<th>Meeting 2</th>
<th>Meeting 3</th>
<th>Meeting 4</th>
<th>Meeting 5</th>
<th>Meeting 6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nutrition</td>
<td>Palliative care</td>
<td>Living close to someone severely ill</td>
<td>How to handle daily life</td>
<td>When life is on the edge</td>
<td>Me as a caregiver</td>
</tr>
<tr>
<td>Nutrition nurse or dietician</td>
<td>Physician</td>
<td>Social worker</td>
<td>Physiotherapist Occupational therapist</td>
<td>Hospital priest</td>
<td>Group leaders</td>
</tr>
</tbody>
</table>

5 min
Participants arrive. Group leaders welcome the group. Efforts are made to make participants feel comfortable.

30 min
Free conversation, supported by the group leaders and all participants are invited to talk about their present situations. Tea, coffee and sandwiches are served.

50 min
The professional guest arrives and the topic of the day is presented. During the presentation, the participants are invited to reflect on and discuss the topic.

5 min
The group leaders conclude the meeting.
Settings
The intervention was delivered at three settings (A, B, C), and a fourth setting (D) was included for comparisons.

Intervention setting A was a specialist palliative care unit in a large city in the middle of Sweden. The unit provided care for about 100 severely ill, dying patients with life-threatening illness (mostly cancer diagnoses) and their families. The patients had an average life expectancy of three months. The unit consisted of an advanced home care section integrated with an inpatient ward, meaning that the same caring team cared for the patients whether they were at home or on the ward.

Intervention setting B was a specialist palliative care unit in a medium-large city in the south of Sweden, providing care for approximately 60 severely ill, dying patients. Again, in this setting most of the patients had cancer diagnoses and the average life expectancy was three months. The patients were cared for via advanced home care or at an inpatient hospice/palliative ward, by separate caring teams.

The third intervention setting, C, was a haematology unit in a small town in the middle of Sweden. This setting cared for about 50 patients with malign haematological diseases and brain tumours. The patients were in earlier or later stages of their life-threatening illness. The setting included inpatient and outpatient care and advanced homecare, with separate caring teams.

For the purpose of comparison, a fourth setting was included. This was a specialist palliative care unit in a large city in the middle of Sweden, providing advanced homecare and inpatient care, by separate caring teams, for about 100 severely ill patients. Most patients had cancer diagnoses, and the average life expectancy was about three months.

All four settings delivered 24-hour services and were staffed by multi-professional teams including physicians, registered nurses, enrolled nurses, social workers, psychologists, hospital priests, dieticians, occupational therapists, and physiotherapists. Settings A, B, and D were all specialised palliative care units including inpatient wards and advanced homecare, and thus had many similarities. Setting A had a special approach since the members of the caring team worked at both the homecare section and the ward. Setting C was somewhat different from all the other three since it was not a palliative care unit. However, in Sweden most patients with haematological diseases are cared for at haematology units through the curative and palliative phases of illness, because of the complexity in determining when the palliative phase starts in these diseases.
Study participants and procedure

Participants in all four studies were family members of patients with life-threatening illness at any of the four settings. The family members were either participants in the support group programme, or part of the comparison group. In study I they were termed “relatives” but with the same meaning as in studies II, III, and IV where they were termed “family members”. A family member was defined as “a person close to me” regardless of whether or not they were related to the patient by blood or by marriage. This definition consequently also includes people such as friends or workmates. All family members participating in the support group programme were chosen by the patients in the three care settings. Family members did not have to participate in the study to participate in the support group programme. The characteristics of the study participants are presented in Table 4.

A majority (95%) of the represented patients had a cancer diagnosis, and median time since diagnosis was 82 weeks. Almost 80% were cared for at home, and median time as a patient at any of the actual settings was 10 weeks. Family members cared for and supported the patient for different amounts of time and with different tasks.

Study I

Data for study I was collected during November and December 2004. A total of 40 family members participated in six support groups at intervention setting A between May 2003 and October 2004. A strategic selection was made with regard to the participants’ age, gender, and relation to the patient in order to elicit as many experiences as possible. The selection aimed at having representatives from all groups. The inclusion criterion was to have attended at least five of the six support group meetings. A written request and information about the study were sent to thirteen family members by mail and followed up a few days later with a telephone call. Three people declined, and so a total of ten people were interviewed. Verbal information about the study was given, and signed consent was collected. The participants were given the choice as to where the interview should take place; four participants chose their own homes and six chose the caring unit. The length of the interviews varied between 30 and 90 minutes.
Table 4. Study participants and their characteristics

<table>
<thead>
<tr>
<th>Participants</th>
<th>Study I n=10</th>
<th>Study II n=29</th>
<th>Study III and IV n= 78</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Intervention group</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Comparison group</td>
</tr>
<tr>
<td>Characteristics</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age, m</td>
<td>60</td>
<td>56</td>
<td>55</td>
</tr>
<tr>
<td>Gender, n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>8 (80)</td>
<td>18 (62)</td>
<td>49 (63)</td>
</tr>
<tr>
<td>Men</td>
<td>2 (20)</td>
<td>11 (38)</td>
<td>29 (37)</td>
</tr>
<tr>
<td>Employment, n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>5 (50)</td>
<td>16 (57)</td>
<td>44 (56)</td>
</tr>
<tr>
<td>Retired</td>
<td>5 (50)</td>
<td>8 (29)</td>
<td>24 (31)</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>4 (14)</td>
<td>10 (13)</td>
</tr>
<tr>
<td>Cohabit, n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7 (70)</td>
<td>13 (45)</td>
<td>34 (55)</td>
<td>40 (85)</td>
</tr>
<tr>
<td>Relation to patient, n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouses</td>
<td>7 (70)</td>
<td>11 (38)</td>
<td>36 (46)</td>
</tr>
<tr>
<td>Adult children</td>
<td>3 (30)</td>
<td>11 (38)</td>
<td>21 (27)</td>
</tr>
<tr>
<td>Parents</td>
<td>0</td>
<td>11 (3)</td>
<td>5 (6)</td>
</tr>
<tr>
<td>Others</td>
<td>0</td>
<td>6 (21)</td>
<td>16 (21)</td>
</tr>
</tbody>
</table>

Study II, III and IV
Between January 2009 and December 2009, eleven support group programmes were conducted: four in setting A, four in setting B, and three in setting C. A total of 86 family members took part in these programmes. All group participants initially received written information about the study, and I also visited all the groups at their first meeting to give oral information and to answer questions about the study. A total of 78 family members agreed to participate. Study participants were surveyed at two time points: the start of the programme (baseline) and within one week after completion (follow-up, 7 weeks). The data collection consisted of a ques-
A support group programme

Anette Henriksson

A questionnaire including sociodemographic information and six validated self-rated instruments assessing preparedness for caregiving, competence for caregiving, rewards of caregiving, anxiety and depression symptoms, hope, and health. Family members in the comparison unit received written information about the study and an invitation to participate, delivered consecutively by nurses at the care unit; 47 of them gave their consent. This procedure is illustrated in fig 1.

Before this procedure took place, three of the instruments used (the Preparedness for Caregiving Scale, the Caregiver Competence Scale, and the Rewards of Caregiving Scale) were translated and adapted to Swedish conditions by me and my supervisors, since there were no such instruments in Swedish. The translation and adaptation were carried out according to Beaton et al. The translated and back-translated versions of the scales were assessed by the authors along with an expert group including nursing researchers who also critically reviewed the items to ensure the linguistic correctness, to grasp the cultural meaning, and to maintain the content validity of the scales at a conceptual level. The Swedish versions were pilot tested in a sample of nine family members of persons with life-threatening illness, in order to evaluate the clarity of the instructions, items, and response format. In study III, baseline data from the intervention group and comparison group (n=124) were used to evaluate the scales. In addition, follow-up data from the comparison group were used to assess the stability of all three scales.

Study IV used baseline and follow-up data from the intervention group and the comparison group. After attrition, 62 persons (79%) in the intervention group and 33 (72%) in the comparison group completed both assessments.

After half the study period (January–June 2009), six support groups had been conducted (two in each of the three settings) and 39 family members had participated. Participants in these groups received a letter after the last meeting with an invitation to participate in study II, which was followed up by a phone call. Three persons declined to participate in the study. Seven persons were excluded; two of them attended only the first meeting, and five could not be reached despite several attempts by telephone. Thus, a total of 29 persons participated in the study, all of whom gave their written consent. The interviews took place approximately 2 days to 1 week after the last meeting of the support group, and family members were given the opportunity to choose the day and time.
Data collection
A comprehensive and multifaceted understanding of the support group programme was required and so a combination of qualitative and quantitative methods was chosen. The terms “qualitative” and “quantitative” refer both to the method of data collection and to the type of data collected. The choice between qualitative and quantitative methods is based on the type of research design and research questions and a combination of the two is common.

Qualitative methodology
Qualitative data collection methods are often flexible and capture verbatim information and/or observable characteristics. Qualitative methodology facilitates study of depths and detail and typically produce a wealth of detailed information about a smaller number of persons and cases. This increases the depth of understanding of the cases and situation studied.

Interviews
The purpose of interviewing is to allow us to enter into another person’s perspective. Qualitative interviewing begins with the assumption that the perspectives of others are meaningful, knowable, and able to be made explicit. Using this assumption, an interview can be used to capture how a person experiences things and gives them the opportunity to speak about their experiences in their own words.

Study I
In study I, qualitative interviews in the form of open face-to-face dialogues were chosen as the data collection method and an open phenomenological approached was used. According to Giorgi this approach calls for an attempt for the interviewer to place both common sense and scientific foreknowledge about the phenomena within parentheses. This has also been called to “bracket” one’s preunderstanding. However, it has been argued that an absolute absence of presuppositions not is possible. Rather, the researcher should be aware of and to some extent restrain and make a critical analysis of his or her presuppositions. The open phenomenological approach aims to understand the world from the other person’s point of view and to understand the meaning of their experiences. The phenomenological ideal is one of listening without prejudice allowing the informant’s descriptions of their experiences to unfold without interrupting them with questions and the presuppositions these involve. With this in mind, the interviews started with the following question: “How did you experience the participation in the support group programme?” The inter nervous system.
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viewer tried not to take anything for granted, but posed questions in a neutral way and used follow-up questions, probing questions, repetition and silence in order to allow and encourage the informant to recount more, deepening their narrative. The interviewer sought to create an atmosphere where the informant felt free to be as open as possible. It was emphasised that positive and negative experiences about participating in the programme were equally important.

Study II
The data collection in study II took place via telephone interviews. Every phone call started with the interviewer making sure that it was a suitable time for an interview, and offering to call back later if the timing was bad. The interviewer then initiated the interview and questions were asked about the support group programme design. A semi-structured interview guide was used to achieve the aim of the study. The guide contained an outline of topics to be covered, with suggested questions. The aim was to ask all the questions of all participants, to get as varied a picture of the support group programme design as possible. The interviewer asked participants to describe their experiences relating to each of the topics covered in the group meetings, to say what was more or less valuable, and to point out whether there were any missing topics. Questions were also asked about the structure of the programme and the group meeting experience. The interviewer used follow-up questions, probing questions, and repetition, to get as rich as possible descriptions of the programme design. It was difficult to leave room for silence and time for reflection during the phone interviews, as facial expressions and body language could not be seen. It was also difficult to know whether silence was an indication of reflection or whether it just meant that the informant was waiting for the next question. Special attention was therefore paid to tone of voice and silences.

Quantitative methodology
Quantitative methodology requires the use of standardised instruments so that the varying perspectives and experiences of different people can be fitted into a limited number of predetermined response categories to which numbers are assigned. Quantitative methods necessitate substantial knowledge of the phenomenon which are to be studied, in order to develop or find any existing instruments to measure these phenomena. The advantage of a quantitative approach is that it makes it possible to measure the experiences of a great many people using to a limited set of questions, thus facilitating comparison and statistical aggregation of the data. This
gives a broad and generalisable set of findings which can be presented succinctly and parsimoniously. 118

Instruments
Six validated self-rated instruments were used to investigate the effects of the intervention. Three of the instruments were translated into Swedish before use. All measurements were chosen on the basis of the conceptualisation and aim of the intervention, along with the findings from study I.

Study III
Three instruments were used to collect data in study III. The instruments were translated into Swedish and psychometrically evaluated, and are described below.

The Preparedness for Caregiving Scale (PCS) was originally developed in the USA for use among caregivers of frail elderly persons living at home. 115 It assesses caregivers’ readiness to provide care. The scale consists of eight items, each responded to on a five-point Likert-type scale ranging from not at all prepared (0) to very well prepared (4). A total score ranging from 0 to 32 is calculated by summing the responses for all items, with a higher score indicating more feelings of preparedness. Unidimensionality and satisfactory internal consistency have been demonstrated by principle component analysis (PCA) and Cronbach’s alpha ($\alpha = 0.93$) among caregivers of patients in palliative care. 123

The Caregiver Competence Scale (CCS) was developed in the USA for use among caregivers of patients with dementia. 124 It measures caregivers’ perceived adequacy of performance. The scale consists of four items, each responded to on a four-point Likert-type scale ranging from not at all competent (0) to very competent (3). A total score ranging from 0 to 12 is calculated by summing the responses for all items, with a higher score indicating more feelings of competence. The scale has demonstrated good validity and reliability in caregivers of patients in palliative care. Unidimensionality has been demonstrated with PCA and internal consistency with Cronbach’s alpha ($\alpha = 0.86$). 123

The Rewards of Caregiving Scale (RCS) was developed in the USA for use among caregivers of patients with dementia. 125 It consists of three subscales measuring rewards of caregiver learning, rewards of being there, and rewards of meaning for oneself. The present study used an abbreviated version including 10 items, excluding the learning subscale since it focuses on caregivers for the elderly. Psychometric testing suggests that one overall score should be preferred over subscale scores. 123 All items are assessed on a five-point Likert-type scale ranging from not rewarding at all (0) to a
great deal of reward (4). A total score ranging from 0 to 40 is calculated by summing the responses for all items, with a higher score indicating more feelings of reward. The 10-item version of RCS has shown good validity and reliability among caregivers of patients in palliative care. Unidimensionality has been demonstrated with PCA, and internal consistency with Cronbach’s alpha ($\alpha = 0.93$). \(^{123}\)

The PCS, CCS, and RCS were chosen since preparedness, competence, and rewards have been confirmed as being concepts with the power to support wellbeing and protect against negative consequences related to caregiving. In addition, the results in study I included several experiences related to these three concepts. The instruments have previously been used together in studies on family members in palliative care.

Study IV
In study IV, six validated instruments were used for data collection in a baseline and a follow-up assessment. The first three of these were the PCS, the CCS, and the RCS, which are described above.

The Hospital Anxiety and Depression Scale (HADS) \(^{126}\) was developed in the UK for use in a medical out-patient clinic among (non-psychiatric) patients aged between 16 and 65. It is designed to detect the presence and severity of anxiety and depression symptoms. It includes two subscales, one for anxiety (HAD-A) and one for depression symptoms (HAD-D), each comprising seven items on a four-point Likert-type scale. A total score ranging from 0-21 can be calculated for each subscale. Higher scores indicate more severe anxiety or depression symptoms. Scores are divided into a number of cut-off ranges: normal (0-7), mild (8-10), moderate (11-14), and severe (15-21). A Swedish version has been developed \(^{127}\) with a Cronbach’s alpha of 0.86 for HAD-A and 0.82 for HAD-D. HADS has been tested and used in samples of family members in palliative care. This instrument was chosen because anxiety and depression among family members are well known as negative consequences of caregiving. The results in study I also included some reports of the participants feeling anxious and worried.

The Herth Hope Index (HHI) \(^{128}\) was developed in the USA to assess hope in adults in clinical settings. It measures hope with 12 items, each answered on a four-point Likert-type scale. A total score ranging from 12-48 is calculated by summing the responses for all items, with a higher score indicating higher hope. HHI is multidimensional and has three subscales: temporality and future, positive readiness and expectancy, and interconnectedness. A Swedish version \(^{129}\) with a Cronbach’s alpha of 0.84 was used. HHI was chosen because hope has been found to be an important...
concept in palliative care as an important aspect of wellbeing. Aspects of hope could also be seen in the results in study I.

The Health Index (HI)\(^{130-132}\) consists of ten items with four response categories: very poor, rather poor, rather good, and very good. Eleven items concern energy, temper, fatigue, loneliness, vertigo, sleep, pain, bowel function, and mobility and general health. A total score ranging from 11 to 44 is calculated by summing the responses for all items, with a higher score indicating better perceived health. A Swedish version\(^{40}\) with a Cronbach’s alpha of 0.89 was used. This instrument was chosen because studies have reported caregiving-related health problems among family members. Some of the items could also be related to results in study I, for example fatigue, loneliness, and temper.

All instruments are attached in the appendix.

**Analyses**

**Phenomenological analysis (study I)**
Phenomenology aims to describe the world as people experience it and to seek out patterns with the purpose of capturing the essence of the studied phenomena. A phenomenon can be understood as it is apprehended, perceived or experienced by individuals.\(^{121}\) The analysis in study I was performed according to the phenomenological method as described by professor Amedeo Giorgi.\(^{119,133}\) All interviews were transcribed verbatim and then read simultaneously while the taped interviews were listened to. This was done to acquire an understanding of the participants, for the language used and to get an overall sense for the material. The text was thereafter re-read and units of meaning were derived. The unit meanings were transformed through a number of steps, which involved concentrating the original text and transforming the participant’s spoken language to a condensed, written language seen from a nursing perspective. The units of meaning were synthesised into a structure for each interview where several key constituents were generated. Each synthesis was thereafter re-read several times and put in relation to the others. In the end, all the syntheses were compiled into a general structure with six key constituents. An overall essence or underlying meaning in all key constituents was identified and formulated.

**Qualitative content analysis (study II)**
One characteristic of qualitative content analysis is that the method, to a great extent, focuses on the subject and context, and emphasises differences similarities within data. In study II telephone interviews were analyzed
using qualitative content analysis. All interviews were transcribed verbatim and then listened to again to confirm the transcribed text. The texts were re-read to gain an overall impression of their content; then while bearing in mind the aim of the study, the text was divided into meaning units. The meaning units were condensed without changing their central messages and thereafter coded. These codes were put into matrices to make it easier to get an overview and to compare them with each other in terms of differences and similarities. Finally the codes were sorted into categories. According to Graneheim and Lundman categories are seen as representing the manifest content, that is the content aspect (what the text says).

Statistical analyses (study III and IV)
In the studies using quantitative methodology descriptive and inferential statistics were used.

Study III
*Distribution of item and scale scores:* Frequencies, medians and quartiles were used to describe item and scale scores. The distributions of item responses were calculated to identify floor and ceiling effects. The D’Agostino normality test was used to evaluate whether the scale scores deviated from a normal distribution.

*Unidimensionality:* Confirmatory factor analyses were used to confirm the unidimensionality of the Swedish versions of the PCS, CCS and RCS. The guiding principles described by Brown, were followed and different fit indices were used to evaluate the goodness-of-fit between the measurement models and the data.

*Convergent validity:* To evaluate convergent validity, Spearman’s correlation coefficients were calculated between the PCS, CCS and RCS.

*Reliability:* Internal consistency reliability was evaluated with Cronbach’s alpha coefficient. As alpha is a lower bound of reliability, a one-sided 95% confidence interval was calculated for each scale based on a method described by Kristoff. Stability was evaluated with intra-class correlations (one-way random model) for paired measures.

The level of statistical significance was set to $p < 0.05$.

All analyses were performed with version 11.1 of Stata for Windows (Stata Corporation, College Station, TX USA) and version 8.80 of Lisrel (Scientific Software International Inc., IL, USA).

Study IV
*Person mean imputation:* Missing values were replaced using a person mean imputation.
Student’s t-test and $\chi^2$-test Baseline characteristics of the intervention group and comparison group were compared using t-tests for continuous variables and $\chi^2$-tests for categorical variables. Dependent samples t-tests were used in each group to examine the effect of the intervention within the group, while independent samples t-tests were used to examine the effect of the intervention between groups, by comparing mean differences between baseline and follow-up.

Effects size: Cohen’s $d$ was calculated to assess the effect size with 0.2 considered a low effect size, 0.5 considered medium, and 0.8 considered high.

Reliability: Cronbach’s alpha was used to assess internal consistency. A $p$-value <0.05 was considered significant.

The analyses were performed with version 19 of SPSS for Windows (SPSS, Inc., Chicago, IL, USA and version 11.1 of Stata for Windows (Stata Corporation, College Station, TX USA).
Ethical considerations

Ethical principles of clinical research, i.e., autonomy, beneficence, non-maleficence and justice have guided these studies and were followed throughout the thesis. Initially heads of the involved four settings received written and verbal information about the studies and agreed for the settings to participate. This was followed by written and also verbal information in arranged meetings with the nurses, at all the settings, since they were asked to deliver written information, invitations and study requests to family members. Family members who participated in the support group programme received both written and verbal information about the studies. Family members in the comparison group received written information with an invitation to call or e-mail the researchers if they had questions or comments about the study. The written information emphasised the voluntary aspect of participation and the right to at any time withdraw from the study without explanations or reasons. The information also explained about confidentiality, data storing and participant’s right to take part of their personal data. It was also accounted that the research findings would be presented in scientific literature and in a thesis. All study participants gave their informed consent in the form of a signed document.

Several ethical questions were considered in planning and performing the studies in this thesis. Importantly, family members in the intervention group could join the support group programme without participating in the studies; they could withdraw from the group without giving a reason whenever they wanted, they could withdraw from the studies while remaining in the support group. Family members in the comparison group received information that their participation aimed to be used for comparisons. Often participants in comparison groups are invited to an alternative support intervention or put on a waiting list to be invited to the studied intervention. This was however not possible within this project.

Interviews on matters that might be associated with strong emotions for individual participants can result in ethical conflicts between the knowledge desired by the researcher and the possible harm to the interviewee. Those people that were interviewed in this thesis were family members of severely ill patients with life-threatening illness. They were in a stressful life situation caring for someone close to them. Some were even in early bereavement. It was assumed that the interviews could actualise emotions and extra effort was put into sensitivity to face expressions, voice tones, silence and pauses. We also considered the fact that answering questions in a questionnaire concerning the situation in being a family member to a person with life-threatening illness could be emotional. All participants in
intervention and comparison group were encouraged to contact the researchers if any concern or question related to the study appeared. No one phoned; however a few (from the comparison group) left short written messages in the questionnaires where they stressed the importance of the study. Ethical approvals were obtained from a Regional Ethical Review Board in Uppsala, Sweden (2008/341, 04-212/1).
Results
The overall results from the studies show that the support group programme could make an important contribution to supporting family members in palliative care. The experiences of participants revealed in study I and II, along with the quantitative results of study IV made it clear that the programme was effective in certain domains related to caregiving. The results will be presented in four parts: experiences of participating in the support group programme (I, II); experiences of the support group design (I, II); the PCS, CCS and RCS (III); and effects of the support group programme (IV).

Experiences of participating in the support group programme
Experiences of participating in the support group programme were found in study I and II. Participation in the programme gave family members a sense of belonging, a feeling of being confirmed, insight into the gravity of the illness and a moment of rest. Altogether this resulted in a sense of safety. These main results are presented below in more detail.

A sense of belonging
Even from an early stage, the conversations in the group gave the participants a sense of mutual affinity based on the similarity of their situations: everyone there understood what they were going through (II). The clear sense of belonging experienced by the participants in the support group programme may in fact be one of the most important findings in this thesis (I, II). This sense of belonging was created by the participants sharing a similar life situation and experiences, and was not dependent upon age, gender or relationship to the patient (I). The participants found it somewhat liberating to have this similar experiences since it excused them from the unnecessary questions and the obligation they often felt about explaining to others what they were going through (I, II). The participants felt that there was a warm atmosphere in the group which permitted and encouraged them to address personal matters, which were received with interest from the others and also guided much of the conversations (II). This created a real feeling of community and with time they shared, many things about themselves. The meetings were an opportunity to compare and identify with others, which sometimes helped the participants to handle the situation and reflect upon positive aspects (I). Within the group, they could even talk about what they perceived as the most forbidden of thoughts: anger and annoyance toward the patient, the disease, and this unwanted change in their lives. These were things that were hard to talk about with
anyone else (II). Some participants did not receive the expected response when giving expression to their own thoughts and reflections which they found disappointing (I). However, most participants felt that support was exchanged between them, and despite their own stressful situation, it was satisfying to provide support to the others in the group (I, II).

**Confirmation**

It was in many ways confirming for family members to be invited to the support group programme. It gave them a sense of importance, and they felt seen and confirmed as individuals with their own feelings, thoughts, and needs. The information given in the support group sessions and the accompanying discussions was affirmative to family members. An important aspect of the feeling of confirmation consisted of meeting others in similar situations and to realising that they were not alone (I, II). It was not perceived as burdening to take part in the other’s experiences; instead, it confirmed their own sorrow (I). They talked about crises and their reactions to them, and many felt reassured in their feelings and thoughts (I, II).

In conversations with members of the caring team, the participants felt valued as individuals, and they positively received the encouragement to prioritise and take care of themselves (II). At the same time as they felt valued as individuals, they also felt valued as an important resource for the patient. When attending the group, family members experienced appreciation from the patient, confirming that they were doing something important. Conversely, by participating in the group, the family members felt they confirmed the patient. Their participation became a statement which signalled to the patient that the family members wanted to be there for them and was available to provide help and support (I).

**Insight into the gravity of the illness**

The information and the discussions in the group gave rise to the insight that the patient would not survive, as family members came to understand the gravity of the illness (I). Most participants considered this insight as something that helped them handle the situation. They said it was important to be confronted with difficulties that would otherwise have been avoided; this prepared them for what was to come. This feeling of preparedness diminished the fear of what would eventually happen and less energy was spent on worrying (I). The feeling of preparedness gave them a feeling of control over the situation, which was helpful in dealing with their feelings of powerlessness over the impending death. For example, one woman said that it was good to receive information bit by bit and step by step, because this made her start the process of realising that her husband
would die from his illness. For some participants, these insights facilitated their acceptance of the present situation, helping them to make good use of the remaining time with the patient (I). Some participants felt distanced from this subject and had difficult perceiving the patient as fatally ill (I). In general, the participants expressed difficult in talking about disease and death in everyday life with the patient as well as in other contexts. The support group meetings triggered and actualised their thoughts about death. The group conversations, however, made this difficult topic somewhat easier to deal with. One man, for example said that the meeting with the priest really made him think and gave him some ideas for ways to handle these questions (II). The participants felt fortified and encouraged to meet the patient in his or hers thoughts about death. For many, attendance at the support group led to increased conversations with the patient, and they felt more empowered to talk about the illness and the fact that it was deadly. These conversations also gave them a chance to straighten out any unresolved issues from earlier in life. Some gained the strength to talk about funeral arrangements which was satisfying in retrospect since it allowed them to arrange the funeral according to the patient’s wishes. Some participants expressed a disliked of being encouraged to talk about death with the patient. They did not want to cause sadness or worries; instead they wanted to protect the patient from such thoughts (I). However, even if; (or perhaps because) this subject was experienced as being difficult to talk about, there were some participants who wanted more information and discussions in the groups concerning death and the actual process of dying (II).

**Being able to rest**
The meetings became a refuge from the otherwise pressured life situation as a family member of someone with severe illness. The participants said that it was very helpful to be given access to information and not have to spend time and energy looking for it (I). The participants saw the support group as a forum solely for them, where they could openly conduct conversations. It was restful to be with others who understood because they did not have to dissimulate their feelings or experience unwanted demands. The participants felt restful just being allowed to be (I, II). Many said that they always felt sad on the inside, but tried to appear happier and stronger on the outside. Within the group, they felt free to cry and talk; the support group became a place where they could drop the façade they felt they were constantly wearing for themselves, the patient, other family members, and others as well. Dropping the façade could be difficult and arduous, even if it was experienced as restful and relieving afterwards (II). Their moment of
rest was a defensible rest, since they had a good reason for being there; they participated in part for their own needs but also in order to become better able to help the patient. It occurred as a legitimate rest since they had been invited by the caring team. This gave them a moment of relief and a break from caring without having to feel guilty for not attending to the patient's needs. Several participants expressed joy about going to the support group meetings. It was a joy to spend time with the others, and for some it was the only occasion to leave their home. However, for those participants having a patient alone at home, who was anxious or agitated, participation in the group could instead create more stress rather than being restful, because of the feeling of abandoning the patient (I).

A sense of safety
In study I the overall essence or underlying meaning was identified and formulated as a sense of safety, and study II also revealed a sense of safety can also be seen through study II. This sense of safety resulted from the combined experiences from participating in the programme. It can be interpreted as meaning that participants felt safe within their groups. They felt safe enough to relax and take a much-needed moment of rest from their stressful life situation. They also felt safe enough to share their personal feelings and thoughts in the group (I, II).

In the meetings, the participants felt reassured that the caring team were competent and could offer a great deal of help to the patient. They thus felt confident that the patient was being given good nursing care. They felt relieved and comforted when they understood that much could be done to help the patient and relieve the symptoms of the disease. They gained an understanding of the available support and how daily life could be facilitated for the patient and for themselves as family members (I, II).

As a result of this new knowledge and understanding, the participants felt safe in their relation to the patient, the illness, and the caring team. This sense of safety generated a feeling of being able to care for and to face the patient in a better and more assured manner than before. They felt more capable of handling the situation, and several participants felt safe enough to care for the patient at home until death. The participants expressed the feeling of being fortified by new knowledge, which facilitated the care of the patient and also made them feel safer in their caring role. There were also some participants who realised that they did not want, were not able, or were too tired, to care for the patient at home. However, these participants felt sufficiently safe to convey this to the patient and the caring team. According to the participants, this sense of safety benefited themselves as well as the patient. Several participants claimed they felt that
the patient had had a rewarding end of life, partly due to the sense of safety gained by the participants and its expression in their handling of the situation (I).

Experiences of the support group design
Experiences of the support group programme design were found in studies I and II. These experiences included the participant’s experiences of the support group programme content, structure, and approach. The main results are presented below.

The content reflected everyday life
Overall, the participants were satisfied with the support group programme design, though there were also some suggestions for refinements (I, II). They felt that the topics presented in the program reflected their everyday lives and focused on situations significant to their lives with severely ill persons (II). In general, the participants expressed that the theoretical information and the practical demonstrations in combination with discussions in the group had increased their knowledge and understanding. This helped them handle the situation and facilitated their caring for the patient. As a consequence, some of their concerns in daily life were relieved. The theoretical information provided in the programme included information about disease and symptoms, crises and grief reactions as well as financial guidance. Practical demonstrations including subjects such as nutrition, physical care, or practical aid were appreciated by the participants and also easy to apply later on at home (I, II). For example, the participants really appreciated the practical suggestions for things they could do to make it easier for the patient to eat and several had tried some of the recipes at home (II). By receiving this information and demonstration, they felt that their participation in the support group was directly or indirectly benefiting the patient and they felt able to manage the care more professionally than before (I). Suggestions for additional topics in the programme were coverage of how to approach and to talk to children when a parent or grandparent is severely ill. Some participants wanted more information and discussions concerning death and dying. One participant expressed a wish to talk about changes in sexuality.

The structure offered an opportunity to establish relationship
The program was structured to begin, with half an hour for conversation, coffee, and sandwiches, followed by input from professionals; this offered an opportunity to establish relationships. An important feature was that the group leaders and guest professionals were members of the team caring
for the patient. The participants were able to meet members of all the professions, which were seen as advantageous (I, II). Many expressed positive feelings about the meetings being held at the care units, which allowed them to move around and become somewhat familiar with the environment. As a result, they obtained a clearer view of the care unit’s organisation, the professional staff categories and the assistance available to them. The participants felt that they had developed a trusting relationship with members of the caring team. It became clear to the participants that they were an important resource for the patient and they felt as though they were caring for the patient in collaboration with the professional team (I). They felt invited and encouraged to get in touch, and several participants contacted the various members of the team for consultation and help after the meeting (I, II).

The participants felt that weekly meetings were needed for continuity and that the schedule was not too time consuming. Most of them felt that 90 minutes was about the right duration, because talking about difficult subjects was sometimes a strain. However, there were suggestions about having flexible time schedules for each meeting, to avoid the interruptions in valuable and emotional discussions which sometimes occurred (II). Some participants would have preferred to be invited to a support group programme earlier in the disease trajectory, whereas others would have preferred to be invited later on. Group size was important; participants in smaller groups tended to be disappointed because the discussions became less productive and participants did not open up to the same extent. This was described by participants in a group that after some attrition consisted of only three persons (II). Overall, the conversation with others was much appreciated and many wanted more time with the group specifically for talking (I, II). During these conversations they spoke about life, gave each other advice on how to find solutions to problems encountered in everyday life, and they shared their attitudes towards the illness and how to handle the current life situation (I). Almost all participants placed high value of the first half hour, which seemed to be an important part of the program (I, II).

**An open approach contributed to a warm atmosphere**

A warm atmosphere was created through a sense of shared responsibility in the group. Many participants talked sincerely about the group leaders as important contributors to the feeling of a warm atmosphere. The group leaders were seen as companions who shared feelings and thoughts and gave advice and support in relaxed conversations (II). No one was appointed as the expert; instead the group’s shared resources were used in the
conversations, as everyone had experience and knowledge about the topics being discussed. The warm atmosphere allowed participants to talk about difficult subjects. Several participants experienced emotional support, since the atmosphere was calm and peaceful.

The PCS, CCS and RCS
The results demonstrated that the Swedish versions of the PCS, CCS and RCS were valid and reliable for use among family members of persons with life-threatening illness.

Unidimensionality
Confirmatory factor analyses confirmed the proposed structure in each of the three scales, an indication of unidimensionality (table 5). Factor loadings varied between 0.70-0.93 for PCS, 0.79-0.97 for CCS and 0.68-0.88 for RCS. All scales had good psychometric properties.

Distribution of item and scale scores
No floor or ceiling effects were shown for the item scores in the PCS. The CCS and RCS showed ceiling effects but no floor effects for all items, with the sole exception of item 3 in CCS, which demonstrated neither floor nor ceiling effects (table 6).

Convergent validity
Convergent validity was supported. PCS and CCS correlated most strongly with each other but there were also significant correlations between all the scales.

Missing data patterns
There was an overall low frequency of missing data. The PCS and CCS had the lowest frequency of missing data. All missing data in the PCS were related to one individual. Missing data in the CCS were related to four individuals who did not respond to any items in the scale. The RCS had the most missing data; these were related to ten individuals, four of whom did not respond to any items in the RCS.

Reliability
All scales demonstrated satisfactory stability, with ICC ≥0.70 despite six weeks between test and retest, and the unstable life situation of the respondents. Cronbach’s alpha indicated high internal consistency for the items comprising each scale; all scales demonstrated alpha values of 0.9 or higher.

Table 5. Confirmatory factor analyses for the Preparedness for Caregiving Scale, Caregiver Competence Scale and Rewards of Caregiving Scale

<table>
<thead>
<tr>
<th>Scales and items</th>
<th>Factor loadings</th>
<th>Measurement error variance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preparedness for Caregiving Scale (n=124)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 How well prepared do you think you are to take care of your relative/friend’s physical needs?</td>
<td>0.75</td>
<td>0.43</td>
</tr>
<tr>
<td>2 How well prepared do you think you are to take care of your relative/friend’s emotional needs?</td>
<td>0.81</td>
<td>0.35</td>
</tr>
<tr>
<td>3 How well prepared do you think you are to find out about and set up services for your relative/friend?</td>
<td>0.89</td>
<td>0.20</td>
</tr>
<tr>
<td>4 How well prepared do you think you are for the stress of caregiving?</td>
<td>0.90</td>
<td>0.20</td>
</tr>
<tr>
<td>5 How well prepared do you think you are to make caregiving activities pleasant for both you and your relative/friend?</td>
<td>0.91</td>
<td>0.17</td>
</tr>
<tr>
<td>6 How well prepared do you think you are to respond to and handle emergencies that involve your relative/friend?</td>
<td>0.89</td>
<td>0.20</td>
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<tr>
<td>7 How well prepared do you think you are to get the help and information you need from the health care system?</td>
<td>0.70</td>
<td>0.51</td>
</tr>
<tr>
<td>8 Overall, how well prepared do you think you are to care for your relative/friend?</td>
<td>0.93</td>
<td>0.14</td>
</tr>
<tr>
<td>Caregiver competence scale (n=119)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 How much do you believe that you’ve learned to deal with very difficult situations?</td>
<td>0.79</td>
<td>0.38</td>
</tr>
<tr>
<td>2 How much do you feel that all in all, you’re a good caregiver?</td>
<td>0.94</td>
<td>0.13</td>
</tr>
<tr>
<td>3 How competent do you feel?</td>
<td>0.97</td>
<td>0.06</td>
</tr>
<tr>
<td>4 How self-confident do you feel?</td>
<td>0.80</td>
<td>0.36</td>
</tr>
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<td>Rewards of Caregiving Scale (n=115)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 Does caring for your relative/friend help you feel like you are doing something important?</td>
<td>0.78</td>
<td>0.40</td>
</tr>
<tr>
<td>2 Does caring for him/her help you feel good about yourself?</td>
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<td>0.42</td>
</tr>
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<td>3 Is it rewarding because you feel you make life a little easier for your relative/friend?</td>
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</table>
Table 6. Item description, score distribution and missing data for the Preparedness for Caregiving Scale, Caregiver Competence Scales and Rewards of Caregiving Scale

<table>
<thead>
<tr>
<th>Scales and items</th>
<th>Median (q1-q3)</th>
<th>Lowest score, %</th>
<th>Highest score, %</th>
<th>Distribution test p-value</th>
<th>Missing data, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preparedness for Caregiving Scale (n=124)</td>
<td></td>
<td></td>
<td></td>
<td>0.597</td>
<td>0 (0)</td>
</tr>
<tr>
<td>1 How well prepared do you think you are to take care of your relative/friend’s physical needs?</td>
<td>16 (12-21)</td>
<td>2 (2-3)</td>
<td>7</td>
<td>8</td>
<td>0 (0)</td>
</tr>
<tr>
<td>2 How well prepared do you think you are to take care of your relative/friend’s emotional needs?</td>
<td>2 (1-3)</td>
<td>4</td>
<td>7</td>
<td>0 (0)</td>
<td></td>
</tr>
<tr>
<td>3 How well prepared do you think you are to find out about and set up services for your relative/friend?</td>
<td>2 (1-3)</td>
<td>2</td>
<td>10</td>
<td>0 (0)</td>
<td></td>
</tr>
<tr>
<td>4 How well prepared do you think you are for the stress of caregiving?</td>
<td>2 (1-2)</td>
<td>9</td>
<td>8</td>
<td>0 (0)</td>
<td></td>
</tr>
<tr>
<td>5 How well prepared do you think you are to make caregiving activities pleasant for both you and your relative/friend?</td>
<td>2 (2-3)</td>
<td>6</td>
<td>6</td>
<td>0 (0)</td>
<td></td>
</tr>
<tr>
<td>6 How well prepared do you think you are to respond to and handle emergencies that involve your relative/friend?</td>
<td>2 (1-3)</td>
<td>11</td>
<td>9</td>
<td>1 (1)</td>
<td></td>
</tr>
<tr>
<td>7 How well prepared do you think you are to get the help and information you need from the health care system?</td>
<td>2 (1-3)</td>
<td>6</td>
<td>11</td>
<td>1 (1)</td>
<td></td>
</tr>
<tr>
<td>8 Overall, how well prepared do you think you are to care for your relative/friend?</td>
<td>2 (1-3)</td>
<td>5</td>
<td>6</td>
<td>1 (1)</td>
<td></td>
</tr>
</tbody>
</table>

Possible score range: Preparedness for Caregiving Scale 0-32; Caregiver Competence Scale 0-12; Rewards of Caregiving Scale 0-40

\(^a\) D’Agostino normality test
### Caregiver Competence Scale (n=119)

<table>
<thead>
<tr>
<th>Question</th>
<th>Preparedness</th>
<th>Frequency</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>1  How much do you believe that you’ve learned to deal with very difficult situations?</td>
<td>6 (4-8)</td>
<td>1 (1-2)</td>
<td>8</td>
<td>19</td>
</tr>
<tr>
<td>2  How much do you feel that all in all, you’re a good caregiver?</td>
<td></td>
<td>2 (1-2)</td>
<td>7</td>
<td>18</td>
</tr>
<tr>
<td>3  How competent do you feel?</td>
<td></td>
<td>1 (1-2)</td>
<td>13</td>
<td>13</td>
</tr>
<tr>
<td>4  How self-confident do you feel?</td>
<td></td>
<td>2 (1-2)</td>
<td>3</td>
<td>18</td>
</tr>
</tbody>
</table>

Possible score range: 0-12

### Rewards of Caregiving Scale (n=115)

<table>
<thead>
<tr>
<th>Question</th>
<th>Preparedness</th>
<th>Frequency</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>1  Does caring for your relative/friend help you feel like you are doing something important?</td>
<td>30 (24-36)</td>
<td>3 (2-4)</td>
<td>1</td>
<td>36</td>
</tr>
<tr>
<td>2  Does caring for him/her help you feel good about yourself?</td>
<td></td>
<td>2 (2-3)</td>
<td>4</td>
<td>17</td>
</tr>
<tr>
<td>3  Is it rewarding because you feel you make life a little easier for your relative/friend?</td>
<td>3 (2-4)</td>
<td>3 (2-4)</td>
<td>1</td>
<td>38</td>
</tr>
<tr>
<td>4  Does caring for him/her add meaning to your life?</td>
<td></td>
<td>3 (2-4)</td>
<td>4</td>
<td>28</td>
</tr>
<tr>
<td>5  Does caring for your relative/friend give you a sense of accomplishment?</td>
<td></td>
<td>3 (2-4)</td>
<td>1</td>
<td>33</td>
</tr>
<tr>
<td>6  Is just ‘being there’ for him/her rewarding to you?</td>
<td></td>
<td>3 (3-4)</td>
<td>1</td>
<td>46</td>
</tr>
<tr>
<td>7  Have you personally grown as a result of being a caregiver?</td>
<td></td>
<td>2 (2-3)</td>
<td>8</td>
<td>15</td>
</tr>
<tr>
<td>8  Do you feel glad that you are the one who is providing care to your relative/friend?</td>
<td></td>
<td>3 (2-4)</td>
<td>6</td>
<td>35</td>
</tr>
<tr>
<td>9  Is caring for your relative/friend rewarding because it makes him/her happy?</td>
<td></td>
<td>3 (3-4)</td>
<td>2</td>
<td>46</td>
</tr>
<tr>
<td>10 Is it rewarding to know that you are helpful to your relative/friend?</td>
<td></td>
<td>4 (3-4)</td>
<td>1</td>
<td>56</td>
</tr>
</tbody>
</table>

Possible score range: 0-40

*D’Agostino normality test*
Effects of the support group programme

Effects of the support group programme were investigated in study IV. A total of 125 family members were included in the study at baseline; 78 in the intervention group and 47 in the comparison group. After attrition, 62 persons (79%) in the intervention group and 33 persons (72%) in the comparison group completed both baseline and follow-up assessments.

Effects on caregiver role outcomes

Family members who took part in the support group programme significantly increased their perceptions of preparedness for caregiving, competence for caregiving and rewards of caregiving between the baseline and the follow-up assessment. In all, 78% of the participants perceived increased preparedness for caregiving, 59% increased competence for caregiving and 53% increased feelings of rewards of caregiving. There were no significant changes in the comparison group concerning preparedness, competence and reward (table 7). When comparing the mean differences, the intervention group showed significant increases in preparedness and competence. A tendency towards an increase was found for reward, but it was not statistically significant (table 8). Effects sizes were high for preparedness, medium for competence and low for rewards (IV).

Effects on physical and psychosocial outcomes

In addition to preparedness, competence and reward the aspects of hope, anxiety, depression symptoms and health were also investigated in relation to participation in the support group programme. No significant changes were shown for hope, anxiety, depression symptoms or health in the intervention group between baseline and follow up assessment (table 7). No significant changes were found in the comparison group and, no mean differences were shown between the groups. (table8)(IV).
Table 7. Baseline and follow up assessments in the intervention and comparison group

<table>
<thead>
<tr>
<th>Measurement</th>
<th>Intervention group</th>
<th></th>
<th></th>
<th>Comparison group</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline, mean (SD)</td>
<td>Follow-up, mean (SD)</td>
<td>p-value&lt;sup&gt;b&lt;/sup&gt;</td>
<td>Effect Size Cohen’s d</td>
<td>Baseline, mean (SD)</td>
<td>Follow-up, mean (SD)</td>
</tr>
<tr>
<td>Preparedness</td>
<td>15.7 (6.3)</td>
<td>19.5 (5.4)</td>
<td>&lt;0.001</td>
<td>0.7</td>
<td>16.5 (7.6)</td>
<td>18.5 (7.2)</td>
</tr>
<tr>
<td>Competence</td>
<td>6.4 (3.0)</td>
<td>7.3 (3.0)</td>
<td>&lt;0.001</td>
<td>0.3</td>
<td>6.7 (2.9)</td>
<td>7.0 (2.6)</td>
</tr>
<tr>
<td>Reward</td>
<td>29.3 (7.9)</td>
<td>30.7 (8.2)</td>
<td>0.015</td>
<td>0.2</td>
<td>28.6 (7.8)</td>
<td>28.4 (9.2)</td>
</tr>
<tr>
<td>Hope</td>
<td>36.4 (5.7)</td>
<td>36.1 (5.9)</td>
<td>0.769</td>
<td>0.1</td>
<td>36.4 (6.2)</td>
<td>35.4 (6.5)</td>
</tr>
<tr>
<td>HAD-A</td>
<td>9.5 (4.8)</td>
<td>8.6 (4.3)</td>
<td>0.114</td>
<td>0.2</td>
<td>9.9 (4.1)</td>
<td>7.8 (3.6)</td>
</tr>
<tr>
<td>HAD-D</td>
<td>6.1 (4.0)</td>
<td>6.7 (4.0)</td>
<td>0.173</td>
<td>0.2</td>
<td>6.5 (3.7)</td>
<td>6.4 (3.4)</td>
</tr>
<tr>
<td>HI</td>
<td>32.1 (6.1)</td>
<td>31.7 (5.5)</td>
<td>0.931</td>
<td>0.1</td>
<td>32.1 (5.3)</td>
<td>31.8 (5.1)</td>
</tr>
</tbody>
</table>

<sup>a</sup> Number of observations varies between measurements depending on missing data

<sup>b</sup> Students t-test (paired)

Preparedness = The Preparedness for caregiving scale; Competence = The Caregiver competence scale; Reward = The Reward of caregiving scale; Hope = Hearth hope index; HAD-A = The Hospital anxiety and depression scale; HAD-D = The Hospital anxiety and depression scale; HI = Health index
Table 8. Mean differences within and between intervention and comparison group

<table>
<thead>
<tr>
<th>Measurement</th>
<th>Intervention group</th>
<th></th>
<th></th>
<th>Comparison group</th>
<th>Mean difference between groups (SD)</th>
<th>p-value&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Effect Size Cohen’s d</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>Mean difference within group (SD)</td>
<td>n</td>
<td>Mean difference within group (SD)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Preparedness</td>
<td>58</td>
<td>3.86 (5.54)</td>
<td>30</td>
<td>0.10 (4.33)</td>
<td>3.76 (1.16)</td>
<td>0.002</td>
<td>0.8</td>
</tr>
<tr>
<td>Competence</td>
<td>59</td>
<td>1.09 (2.09)</td>
<td>31</td>
<td>-0.35 (2.09)</td>
<td>1.44 (0.46)</td>
<td>0.002</td>
<td>0.7</td>
</tr>
<tr>
<td>Reward</td>
<td>55</td>
<td>2.07 (6.08)</td>
<td>30</td>
<td>-0.27 (5.32)</td>
<td>2.34 (1.32)</td>
<td>0.081</td>
<td>0.4</td>
</tr>
<tr>
<td>Hope</td>
<td>58</td>
<td>0.21 (5.34)</td>
<td>31</td>
<td>-1.03 (3.02)</td>
<td>1.24 (1.04)</td>
<td>0.236</td>
<td>0.3</td>
</tr>
<tr>
<td>HAD-A</td>
<td>60</td>
<td>-0.88 (4.26)</td>
<td>31</td>
<td>-1.06 (3.18)</td>
<td>0.18 (0.87)</td>
<td>0.835</td>
<td>0</td>
</tr>
<tr>
<td>HAD-D</td>
<td>60</td>
<td>0.47 (2.62)</td>
<td>31</td>
<td>0.39 (2.65)</td>
<td>0.08 (0.58)</td>
<td>0.892</td>
<td>0</td>
</tr>
<tr>
<td>HI</td>
<td>60</td>
<td>-0.05 (4.47)</td>
<td>33</td>
<td>-0.62 (2.75)</td>
<td>0.57 (0.85)</td>
<td>0.504</td>
<td>0</td>
</tr>
</tbody>
</table>

<sup>a</sup> Students t-test (unpaired)

Preparedness = The Preparedness for caregiving scale; Competence = The Caregiver competence scale; Reward = The Rewards of caregiving scale; Hope = Hearth hope index; HAD-A = The Hospital anxiety and depression scale-anxiety; HAD-D = The Hospital anxiety and depression scale-depression; HI = Health index
DISCUSSION

This thesis focuses on a support group programme for family members of patients with life-threatening illness during ongoing palliative care. The main results show that as a result of participating in the programme, family members experienced safety and a sense of belonging, insight into the gravity of the illness, and a moment of rest in addition to increased feelings of preparedness, competence, and reward. The results also show that the family members experienced the programme as including topics of immediate interest to them, as being structured in a way which offered opportunities to establish relationships, and as having been delivered in a warm atmosphere where they felt reassured and confirmed. Another major result is that the Preparedness for Caregiving Scale, the Competence for Caregiving Scale, and the Rewards of Caregiving Scale were shown to be useful, valid, and reliable for use among family members in palliative care.

Sense of belonging as an expression of social support

The qualitative results clearly point out the importance of meeting, talking to, and listening to other people in similar life situations. These factors were described and experienced as acquiring a sense of belonging, being confirmed by others' experiences, and having the comforting feeling of not being alone. This sense of belonging led the participants to feel relaxed, and to experience a moment of rest during which they could drop their façade for a while since they were with others who understood. The first half hour of the programme, including free conversations among participants and group leaders, was highly valued and appreciated. Most participants also wanted more opportunities to meet and talk with the others. Support is often expressed as that which occurs between professionals and family members and that which occurs between family members and patients, but within the support group another dimension of support appeared. Family members gave and received support to and from other families who were outside their natural social network but who lived in similar situations and had similar experience of life-threatening illness. For many, having the opportunity to contribute their knowledge and experiences, and thereby provide support to the others, was experienced as positive and rewarding. Social support emerged and was exchanged between participants. There are several definitions of social support, as can be seen in the section describing the theoretical standpoints of this thesis. However, according to Moss, social support can be seen as a subjective feeling of belonging and of being accepted, loved, and needed. The opportunity to confide in others appears to be an important component and function of
social support. In the support group, participants confided in each other a great deal; they said things that could not be said to anyone else, and they could even talk about things perceived to be forbidden and taboo. This was probably a result of the warm atmosphere created by both participants and group leaders. Langford et al. provide support for this hypothesis, having argued that socially supportive behaviours cannot occur without a structure of people with the quality of connectedness required to generate an atmosphere of helpfulness and protection. The sharing of experiences underpins most group interventions, and is seen as the most natural form of support. It is known that participation in support groups can result in feelings of belonging, which may be expressed in various ways; for example, as feelings of cohesion and intimacy, of getting help by being with people who understand, and of the great value of sharing experiences with people confronting a similar situation. Feelings of belonging can also be compared with the findings of Stoltz et al., who described the meaning of support for family caregivers as experiencing togetherness with others in caring.

The professional group leaders participated in every meeting; they were seen as companions who led and participated in the conversations within the group. This does not, however, necessarily mean that they were a part of this social support exchange. Many theoreticians have discussed the difficulty of identifying social support versus professional support. Significant differences exist between these two types of support, many of them due to the nature of the relationship between the provider and the recipient of support. A personal relationship between two individuals is based on trust and congruent expectations, while the relationship between a professional and a family member of a patient is based on certain role expectations. It could be said that the sense of belonging was an expression of the exchange of social support between the participants. Social support is known to be an important protector from the harmful effects of caregiving. However, from the results it is also reasonable to state that the participants felt supported by the professionals participating in the programme. It can be assumed that, for example, a major part of their increased knowledge and insight into the gravity of the illness was the result of the professional input. It can probably be concluded that a combination of professional support and social support was the core of the programme.

**Preparedness, competence, and rewards in relation to caregiving**

Approaching caregiving from a caregiver’s perspective provides information about the caregiver’s own perspective of how well care is provided. Concepts that represent caregiver self-perception include preparedness for
Preparedness for caregiving

Participants in the support group programme experienced an insight into the gravity of the illness, and expressed that this resulted in a feeling of being prepared for what was to come. This feeling of preparedness diminished some of their worries and gave them a sense of control over the situation. This was also confirmed in the quantitative results, as participants in the intervention group felt statistically significantly more prepared to care for someone with life-threatening illness after taking part in the support group than they did before. Preparedness refers to how ready caregivers perceive they are for the tasks and demands in multiple domains of the caregiving role, such as providing physical care, providing emotional support, setting up in-home support services, and dealing with the stress of caregiving. Negative correlations have been shown between preparedness and caregiver worry. This strengthens the relation between qualitative and quantitative results in this thesis, as participants expressed less worries and rated higher preparedness after participation in the programme. Caregivers who see themselves as being well prepared in terms of having the relevant support, skills, and knowledge have been shown to also have decreased levels of depression. Conversely, carers who perceive they are inadequately prepared are prone to greater levels of burden including increased strain and tension. Preparedness for caregiving has been associated with generally lower levels of caregiver strain, and among family carers has been shown to have a broad effect on multiple indicators of wellbeing such as fatigue, vigour, confusion, and total mood disturbance. Feelings of high preparedness may also protect caregivers from perceiving caregiving as becoming increasingly difficult as demand increases. Low levels of preparedness, on the other hand, have been associated with more perceived caregiving difficulty and mood disturbance.

Preparedness for death

The studies in the thesis were conducted among family members of persons with life-threatening illness, many with severe, advanced illness close to
death. At follow-up, 29 of the 116 patients had died. The question of family members’ preparedness for the death of their loved ones was not explicitly examined in this thesis. However, the participants expressed that the meetings in the group triggered and actualised thoughts about death. They spoke about developing a feeling of preparedness for what to expect or what was to come, and a readiness to meet the loss of someone close. Preparedness, or the degree to which a family caregiver is ready for the death, has been shown to have different dimensions: knowledge, affective, and behavioural. The knowledge dimension refers to medical, practical, psychosocial, or religious/spiritual information; the affective dimension refers to preparing emotionally for death; and the behavioural dimension refers to tasks.  

This can be compared to the results of Steinhauser et al., who demonstrated preparedness as a complex multidimensional construct consisting of medical (knowing what signs and symptoms to expect), psychosocial (discussing grief and emotions), spiritual (talking about meaning), and practical (arranging for the funeral) dimensions. Although the support group programme did not explicitly focus on preparing for death, it is possible that all three dimensions were concerned, directly or indirectly, since the participants all cared for severely ill, dying persons. It has long been suggested that family members who are forewarned or prepared for death are better able to prepare psychologically. Despite this, family members who provide highly-intensive care often perceive themselves as unprepared for death. Family members who feel unprepared for death also display more depression, anxiety, and complicated grief symptoms. Valdimarsdottir et al. found a dose-dependent relationship between preparedness and psychiatric morbidity; the less prepared bereaved persons felt, the higher the risk of psychiatric complications. It could be assumed that open discussions about death, dying, and bereavement between family members and health care providers would be likely to improve family members’ wellbeing and increase their preparedness for death.

Clear, consistent, and reliable communication is of primary importance in supporting family members to prepare for the death of a loved one. This kind of conversation was possible in the support group, since the atmosphere was seen as warm and inviting in terms of discussing personal, emotional matters. It could be that participation in the programme provided help and facilitated the process of anticipatory grieving, which occurs between a family member’s awareness of impending death and the actual death. Anticipatory grieving is a process of preparing oneself emotionally to live a life without the patient. Andershed found that family members often want to be more prepared for the fact that the patient is seriously ill and dying, and it could be argued that support should...
include preparation for the prospective separation. 

It has been suggested that family members who are well informed, understand the disease process, and feel more prepared through open communication would have fewer difficulties in bereavement. 

If the time before death is fraught due to family members feeling anxious and worried about how to manage the situation, they might remember the patient’s death in a negative light, which may have implications for their own wellbeing during the bereavement.

**Knowledge/competence for caregiving**

It is somewhat complicated to distinguish between expressions of preparedness and expressions of competence. They seem to be closely related, and under some definitions competence is considered a part of preparedness. The participants in the present thesis appreciated the information provided by the professionals and the discussions with others in the group. This increased their knowledge, which contributed to an understanding that helped them handle their situation. They actually perceived this to facilitate the care of the patient. Carlander et al. found that family members wanted to learn caring activities from both professionals and others in similar situations. Participants in the intervention group demonstrated an increased self-rated competence for caregiving after taking part in the support group programme. Caregiver competence as defined by Pearlin et al. is the perceived adequacy of one’s performance as a caregiver. The participants felt more secure in their caring role after participation, and believed they were better able to care for the patient in a more assured way than before. This ties in well with the description of competence as a component of the self concept. Competence relates to the caregiver’s perception of self, specifically as a caregiver. Caregivers who have previous caregiving experience and/or a professional caregiving background seems to be likely to adapt more quickly. It could be that those without this experience may be more likely to take on the role in a trial and error fashion. This could be compared with Mayeroff’s description of caring as a process of going into the unknown. By this, Mayeroff means that caring is not just a matter of good intentions or warm regard, but sometimes calls for special training and ability to care for another person. The ability to care is not simply the desire to care; it is also the ability to cope with and be capable of caring. Caring for a severely ill, dying person demands special skills and abilities from family members. As we know from the literature, family members are often willing to care for someone close; but they may need support to cope, to increase their knowledge, and to be capable of the different tasks involved in caring. In Swanson’s theory of caring,
knowing is striving to understand an event as it has meaning in the life of the other. 97 Participation in the support group might have contributed to an increased understanding and knowledge of severe illness, common symptoms, and the influences on the patient in terms of physical, physiological, and social aspects. This probably facilitated the family members’ understanding of the unique situation of the persons they cared for. This is of importance, since according to Swanson it is how the person cared for experiences the situation that is the starting point for understanding. 97 Gaining information about normal crisis reactions and common ways of coping in relation to severe illness, could help a family caregiver to better understand the patient. Swanson emphasises that in caring we should listen carefully to the person who is cared for, and continuously look for and assess any cues. 97 This is probably easier when the family caregiver knows how and what to look for. As a consequence of increased knowledge and understanding, participants in the support group programme experienced some relief in their everyday life living close to someone with life-threatening illness.

**Rewards of caregiving**

Family members in the support groups had strong feelings of belonging and confirmation, and had an opportunity to rest and reflect upon their life situation. They also experienced increased competence/knowledge and feelings of being able to care in a more assured way then before. This might have contributed to the increased feelings of rewards of caregiving that were found in study IV. It can also be assumed that increased feelings of preparedness resulted in feelings of reward. Here we may refer to the aspects of caring and the philosophical reflections of Mayeroff, who explains that in caring we may help the other person to grow, and thereby we may also grow ourselves. Mayeroff also states that in caring we actualise ourselves, which could be associated with feelings of reward. 95 Andershed showed that family members can feel both gratitude and satisfaction in having being able to manage the caring situation. 10,43 Other studies have shown that the caring experience can be a personal enrichment, giving a feeling of meaning and also contributing to increased insights and knowledge of one’s own. 38,171,172

**The care of the patients**

It seems reasonable that family members, who feel safe, reassured, confirmed, well informed, more prepared, more competent, and sufficiently rewarded in relation to their caregiver role would be likely to provide more optimal care with positive benefits for the patients, an idea which has also
been suggested by others. Several study participants believed that the patient had had a rewarding end of life, partly due to their participation in the support group and its expression in their handling of the situation. However, we do not know whether and how the participation actually affected the care of the patients. To be able to say anything about this, we would have needed to investigate caregiving outcomes including the extent to which the patient’s psychosocial, physical, environmental, and medical needs were met. However, the intervention focused on family members, and the main concern was their wellbeing. When we approach caregiving from a family caregiver’s perspective we reveal information about their thoughts and feelings on how well care is provided, but the wellbeing of the patient is usually not explicitly taken into account. It should however be recognised that it has been shown that when family members do not obtain information or support, their potential for supporting the patient decreases and a caring delay may occur, resulting in suffering for both family members and patients.

**Anxiety, depression symptoms, health and hope**

Even though family members in the intervention group felt statistically more prepared, competent, and rewarded in relation to their caregiving situation, their self-rated levels of anxiety, depression, and health were not influenced by the intervention. It seems reasonable to think that some of the qualitative results (e.g. feelings of belonging, confirmation, safety, a moment of rest, and being able to drop the façade in a warm atmosphere) would influence these outcomes, but this was not shown in the results. However, family members reported only moderate levels of anxiety, and in contrast to other findings there was no indication of depression symptoms in either intervention or comparison group at baseline or at follow-up. In addition, levels of perceived health were high in both groups at baseline and follow-up. This may have been due to the support offered within standard care by the palliative care team. However, it must be remembered that family members with more anxiety, more depression symptoms, and poorer health may be less likely to participate in support groups or research studies.

Levels of hope were high in both the intervention group and the comparison group at baseline and at follow-up. The high levels of hope are not that surprising, as hope has previously been found to be an important concept in palliative care. Family members have expressed hope as a part of finding meaning. According to Mayeroff, hope is an important ingredient in caring. By this, he means that hope is not to be confused with wishful thinking and unfounded expectations, but should be seen as an expres-
sion of a present alive with possibilities; 95 this ties in well with the approach of palliative care. 1 Mayeroff suggests that hope implies that there is something worthy of commitment. 95

The support group participants received information and were invited to discuss emotive topics related to the illness and impending death of someone close to them. It is therefore noteworthy that no negative consequences concerning anxiety, depression, health, and hope were found for family members in the intervention group.

**Interventions for family members during ongoing palliative care**

Working to support family members during ongoing palliative care can be a rewarding and challenging process. Within palliative care, there has always been a strong emphasis on supporting family members, although there is little guidance as to what such support involves or indeed how to achieve it. In the work of developing interventions, we have to consider several questions.

One crucial and as yet unanswered question is that of when the intervention should be offered. Some of the family members investigated in this thesis would have preferred to have been invited earlier in the disease trajectory, but there were also a few who felt they had been invited to participate too early in the disease trajectory, and so felt that the information and discussions in the group were not relevant to them. This ambiguous finding has also been described by others. 64-66 Nolan et al. 177 have suggested that throughout the caregiving experience, family members are likely to engage in “anticipatory care”, which involves anticipating what they would do if the patient should suffer from a real or imagined deterioration. Anticipatory care does not necessarily involve direct caregiving, but may be as just as time-consuming and worrying for family members as more direct involvement in supporting the patient. Nolan et al. 177 have also suggested that the level of information and knowledge that family members have in relation to the disease trajectory can become important in reducing “speculative caregiving”, which is characterised by a lack of information or knowledge about the situation. This can result in over- or under-anticipation of future needs, which may have a detrimental effect on family members. Informed anticipation, on the other hand, can result in greater shared care and planning. 177 This can be compared with the results of Andershed, who found that “to know” was a prerequisite for family members in being able “to be” and “to do” in caring. 17,178 These results are consistent with the ideas of both Mayeroff and Swanson regarding knowledge in relation to caring. It could thus be assumed that early intervention would be preferable, as it would give family members the opportu-
A support group programme

Anette Henriksson

Mckay et al. \textsuperscript{179} suggest that there may be particular times throughout the disease trajectory when family members will have additional support needs. The point of diagnosis can often have a significant and profound effect on the family caregiver, and more specific support needs may arise as the family member becomes increasingly involved in instrumental or “doing for” caring. \textsuperscript{179} The intervention studied in this thesis was offered to family members in the late palliative phase, when the patients were close to death, which is recognised as the most challenging. This is a phase when family members often require active and sustained support to manage the caring as well as their emotions surrounding the impending death. \textsuperscript{180} Difficulties can arise in estimating the best time to intervene with family members, as the very uncertainty of the disease trajectory and potential deterioration in the patient’s condition can make it hard to anticipate future needs. When there is a less clear disease progression and a potentially long illness, expectations of potential time frames from diagnosis to death often become less predictable. It is possible that an ongoing assessment of family members’ needs may highlight the best time for intervention.

The second question is \textit{how} family members should be supported. Interventions can be delivered in several ways, for example face-to-face, by phone or videophone, via booklets, on websites, or in a group format. Some research indicates that individual intervention is to be preferred in palliative care, since family members may have difficulties leaving the patient. \textsuperscript{46,47} However, the support group programme investigated in this thesis was a positive experience for those family members who managed to attend. The participants felt supported and had the opportunity to support others in similar situations, which created an exchange of social support with a sense of belonging; this is a dimension of support that would not be experienced in an individual intervention. This type of support could probably also be experienced in web-based interventions offering interaction between people in similar situations.

The third question is \textit{what} should be included in interventions aiming to support family members during ongoing palliative care. The support group programme included both a supportive and an educational component, which could be one reason for its success. Interventions are often divided into supportive, \textsuperscript{181} psycho-educational, \textsuperscript{57,65,84} and educational types. \textsuperscript{33,182} The results of this thesis seem to favour a format of mixed content combining information and discussions, which has also been emphasised by others. \textsuperscript{183} The content in an intervention for family members during ongoing palliative care could be guided to advantage by the framework described by Andershed, \textsuperscript{43,178} and support family members’ ability “to know”, “to
be”, and “to do”. When discussing what to include in an intervention we need to recognise the very special needs of those participating. Meanwhile, an intervention also needs to be structured, following an intervention manual to ensure consistent delivery of the intervention and to facilitate replication and testing.

The fourth question concerns the dose/duration of the intervention. For what period of time should the intervention last? Most participants in this thesis considered six meetings to be appropriate for this kind of intervention, but they also said they wanted more meetings just for talking to the others in the group. This could be interpreted as meaning that the family members had their educational and informational needs sufficiently met by six meetings, but needed a continuance of the social support they experienced.

A fifth question is how to evaluate and make sure that interventions are sufficiently effective. Careful consideration needs to be given to exactly what the intervention can realistically expect to accomplish, as short term interventions are unlikely to produce global and multidimensional change. For example, it will probably not be considered feasible within a short period of time to lessen depression or enhance physical health. When using an instrument for evaluation, we need good knowledge about the instrument. Instruments should match the aim of the intervention, and should have been tested for use in the relevant population and context and sensitive enough to detect change. If these criteria are not met, we end up with a lack of evidence which may well be a result of the use of inappropriate instruments. A crucial part is of course to investigate the experiences of participants concerning intervention usefulness, accessibility, acceptability, and feasibility.

It could be said that all these questions — when, how, what, for how long, and how to evaluate — depend on the aim of the intervention, which seems to be the most important thing to determine at first, before development, delivery, and evaluation are decided on. A clear and specific aim will probably facilitate the work of developing, delivering, and evaluating an intervention. Furthermore, interventions should be based in theory. In this challenging but rewarding work, we must also remember that the context of caring for a dying relative can be extremely stressful, and it is likely that any intervention to improve support will have only a limited impact on improving the distressing outcome of the experience.
**Methodological considerations**

**The mixed method design**

The main aims of this thesis were to describe experiences of taking part in a support group programme, to describe experiences of the programme design, and to investigate the effects of the programme. Another aim was to translate and psychometrically evaluate instruments that can be used for investigating these effects. To achieve these aims and answer the research questions, both qualitative and quantitative methods were chosen to complement each other and provide a broader knowledge perspective. When using different methods we may find compliance but we may also acquire both breadth and depth in the results. The use of different methods may also allow the strengths of one method to compensate for weaknesses in another. Hence, it could be argued that the results from the mixed methods used in this thesis will broaden our knowledge and give a multifaceted picture of this specific support group programme.

**Researchers preunderstanding**

Before the start of this research project I had worked as a nurse in specialised palliative care for almost 15 years, caring for many patients and supporting their family members. I was a specialist nurse in cancer care, and had extensive knowledge of palliative care and family support. I was involved in the support group programme at one of the settings, both as one of the initiators and as a group leader. However, when the research project started, I ceased my involvement in the delivery of the intervention and my group leader role. Instead I did my best to step into the role of a researcher. When I conducted the data collection for the first study, which was a phenomenological study, I made efforts to be aware of and to restrain my preunderstanding, and to critically question my presumptions about the programme. It must be recognised that there is a general underlying assumption that the intervention should offer support for family members. Without this assumption of doing something good, it would be difficult to engage health care professionals in spending their time and efforts to deliver such an intervention. My supervisors were all registered nurses with many years of experience in research in palliative care. We therefore openly and continuously discussed and challenged our preunderstandings throughout the research project, with the purpose of remaining open to what was really in the data material.
Sample reflections
The participants in the studies in this thesis were a self-selected sample. Self-selection often results in a number of differences between those who choose to participate and those who do not. 145 We should consider that the family members who choose to attend support groups could represent those with a positive attitude as well as the strength and ability to manage their situation quite well already. 70 This is in congruence with the results in study IV; family members reported moderate levels of anxiety and there was no indication of depression symptoms in either intervention or comparison group at baseline or at follow-up. The levels of perceived health were high in both groups at baseline and at follow-up. This may have been due to the support offered within standard care by the palliative care team, but it may also be a consequence of the self-selected sample. It is probable that family members with more anxiety, more depression symptoms, and poorer health are less likely to participate in support groups and research studies. We may thus assume that those most in need of support did not attend the support groups, nor did they participate in the studies. Few negative aspects of the support group programme are evident in the results, even though participants in studies I and II were encouraged to talk about both positive and negative experiences. We should consider that those family members who consented to participate in the studies might have been those with a positive experience of the programme. It should also be recognised that the participants could have felt gratitude toward the caring team, and hence felt somewhat obliged to give positive answers. Finally, the risk of gatekeeping needs to be considered. All participants in the support groups were invited by the researchers to participate in the studies. However, the invitations to join the support groups and the written study invitations to family members in the comparison group were delivered by the nurses at the study settings. These nurses could have refrained from inviting certain family members in order to protect them, thinking they might not have the strength, time, or desire to participate. These family members might also have been in need of support.

Trustworthiness (study I and II)
In qualitative research the concepts credibility, dependability and transferability have been used to describe various aspects of trustworthiness. 134,190,191 Credibility covers issues such as the choice of participants. 134 Participants with various experiences should be chosen to increase the possibility of shedding light on the research question from a variety of aspects. 118 Another important aspect of credibility lies in selecting the most appro-
appropriate method for data collection. Study I used a phenomenological approach, with open interviews being conducted with 10 participants in order to obtain rich and detailed descriptions of experiences of participating in the support group programme. A strategic selection was made with regard to the participants’ gender, age, and relation to the patient. However, the sample was not as varied as would have been ideal, since it reflected the participants in the support groups with a majority of women and spouses. The data collection method was chosen in order to ensure depth in the results. In study II, semi-structured qualitative interviews were conducted by phone with 29 participants in order to get as many and as varied descriptions of the programme design as possible. This data collection method was chosen to ensure breadth in the results. Credibility also concerns the choice and the process of the analyses. According to Giorgi, verification of a phenomenological study entails trying to clarify the conditions under which the results were found. This means that it is the research process that should be verified, rather than the results themselves. Thorough, rich descriptions of the whole research process and, perhaps more importantly, of the analytic process, allow the reader to determine the quality of the study. In study I, the two authors collaborated in the process of analysis. The transformation of meaning units into structures and key constituents was repeatedly discussed. Both authors were involved in the identification and formulation of the overall essence. The data material in study II was suitable for qualitative content analyses. The transcribed interviews were partly read by three of the authors. The process of condensing and coding the meaning units was continuously discussed and partly performed jointly. These codes were put into matrices, and the authors cooperated in comparing these with each other based on differences and similarities. Finally, the codes were sorted into categories representing the manifest content in the text. However, reviewing the results in retrospect, parts of the result could occasionally be seen as an expression of latent content. Both the preliminary analyses and the more mature manuscripts for studies I and II were peer reviewed in seminars involving researchers experienced in qualitative research. These procedures were performed on the basis of trusting in the value of dialogues between co-authors and other researchers to determine whether or not there is agreement about the way data are labelled and sorted.

Dependability is concerned with the degree to which the data alter depending on the researcher’s skills and abilities. During the data collection for study I, the interviewer worked as a nurse at the actual setting. The participants may therefore have expressed predominantly positive experiences of the programme, avoiding critical comments due to a sense
of gratitude. This could have influenced the results. However, the interviewer tried to create an atmosphere in which the participants felt safe to share both negative and positive experiences. Participants were also encouraged to suggest refinements for the programme. The fact that the interviewer worked as a nurse may actually have contributed to the participants feeling relaxed and confident, resulting in rich and detailed descriptions. The data collection in study II was conducted via telephone interviews, requiring the interviewer to be highly attentive to voice tone and silences. Handling silences in this context was difficult, as silence could indicate a number of things, including that the informant was reflecting upon the conversation or previous question, or maybe that they were just waiting for a new question. These matters might have influenced the results.

Transferability refers to the extent to which the findings can be transferred to other settings or groups. It is for the reader to decide whether or not the results are transferable. To facilitate transferability, the authors of studies I and II tried to give a clear description of the context, selection, and characteristics of the participants, as well as the data collection and analytical process. Emphasis was put on rich and vigorous presentation of the findings, with quotations used for illustration.

Validity and reliability (study III and IV)

Study III was a psychometric evaluation mainly based on confirmatory factor analysis. Some recommendations regarding sample size for confirmatory factor analysis are based on a minimum number of observations independently of the complexity of the measurement model, while other recommendations are based on the ratio of the number of observations to the number of variables. As a rule of thumb, 100 to 200 observations or a ratio of 5 to 20 observations per variable is often used as a minimum criterion. The confirmatory factor analysis in study III was based on a sample size of 115-124 and the ratio of observations for each item was between 11:1 and 29:1; the sample size therefore seems to be sufficient. There is still a risk that the sample was too small to detect deviations between model and data, especially for the RCS, which had the largest number of items and smallest number of observations. However, the use of diverse goodness of fit indices increases the probability of the results being reliable.

Due to the somewhat small sample size, a 95% lower bound confidence interval for Cronbach’s alpha was calculated to ensure that the PCS, CCS, and RCS had acceptable internal consistency reliability.
All scales demonstrated satisfactory stability despite 6 weeks between test and retest and the unstable life situation of the respondents. However, this evaluation was performed in only 30 family members and hence should be interpreted with caution.

Responsiveness was not tested within study III, which somewhat limited the psychometric evaluation since this is an important property of a scale. However, the results of study IV indicate responsiveness in all three scales, but further testing is needed to establish this.

Study IV used a quasi-experimental design with a non-equivalent comparison group. As a consequence of this methodology, participants in the intervention group were significantly younger, more often employed, and less often cohabiting with the patient. In addition, 79% of the comparison group but only 46% of the intervention group was spouses, while 27% of the intervention group but only 15% of the comparison group were adult children. One explanation might be that the whole family was invited to the support groups, and the members of the family agreed among themselves that the adult children should attend the meetings, since it might have been easier for those not living with the patient to take part in the support groups. It should still be recognised that 46% of those in the support groups were spouses. Invitations to participate in the comparison group were delivered in envelopes to the patients’ homes, and so it seems natural that the family member who lived with the patient was the one participating in the study. Importantly, at baseline there were no significant differences between the intervention group and the comparison group regarding the outcomes of the study: preparedness, competence, rewards, hope, anxiety, depression symptoms, and health. This makes us relatively confident that the differences at follow-up were a result of participation in the support group programme. 197

One limitation of the statistical analyses in this study is that the assumption of non-independency was partly violated, as eight patients were represented by two or three family members each. To ensure that the findings were not affected by this, a regression model based on robust variance estimates was calculated for all tested outcomes. 198 The mean difference was included as dependent variable, and group (intervention or comparison) was included as predictor. These analyses demonstrated virtually identical results and therefore justified the use of t-tests based on an independence assumption.

Attrition between baseline and follow-up was 21% in the intervention group and 28% in the comparison group. There were no significant differences between those who dropped out and those who completed the study regarding age, gender, relationship to the patient, or cohabitation. It is a
limitation that the reasons for attrition were not reported, but since 29 patients had died by the time of follow-up it seems reasonable that some patients also died even earlier, during the ongoing intervention, which could be a reason for attrition. However, reasons for attrition in the intervention group could also have included negative experiences or less satisfaction with the programme. Ineligible family members and those who declined to participate in the support group programme were not recorded.

To overcome the limitation that no power analysis was conducted before the study start, Cohen’s effect size was calculated to estimate the importance of the study. Effect size is a way of quantifying the differences between two groups, and has many advantages over the use of test of statistical significance alone; for example, it emphasises the size of the effect rather than confounding this with sample size. 142

Summary of results and conclusions

The results of this thesis can give some guidance for future work in supporting family members of persons with life-threatening illness during ongoing palliative care. The conclusions that we can draw from the results are summarised below.

- Family members taking part in the support group programme felt supported by the professionals, and they also received support from and were able to support the others in the group. Participants felt confirmed with a sense of safety and belonging, they gained insight into the gravity of the illness, and they got a moment of rest. This influenced their possibilities of handling their situation and facilitated their caring for the patient.

- The support group programme was on the whole a positive experience for the family members who participated; they felt that it covered topics of interest which reflected their lives with severely ill patients, was structured in such a way as to make them feel invited by the caring team, and used an open-minded approach that fostered a warm atmosphere in which they shared feelings and thoughts. Participation also offered an opportunity to establish relationships with others in a similar situation. It seems like the programme design including a combination of education and support was a good mixture that was appreciated by the participants.

- The Preparedness for Caregiving Scale, the Caregiver Competence Scale, and the Rewards of Caregiving Scale proved to be valid, reliable, and useful in a population of family members of persons with life-threatening illness. The scales could be used to assess needs and to guide and also to evaluate interventions for family members.

- The support group programme seemed to be effective in certain domains related to caregiving. Participation increased family members’ perceptions of preparedness for caregiving, competence for caregiving, and rewards of caregiving. The intervention had no effects on perceptions of hope, anxiety, depression symptoms, and health. No negative outcomes from the intervention were detected.
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Relevance to clinical practice

The results indicate how important it is for caring teams in palliative care to invite and interact with family members. These findings also offer encouragement in the challenging work of developing and delivering interventions with the explicit purpose of supporting family members. The key strengths of the support group programme studied in this thesis were the nurses from the caring team, who acted as group leaders, and the input of the multi-professional team. The results also prove that it is possible to perform group interventions during ongoing palliative care that create positive experiences and an exchange of social support between participants. This programme emphasised the needs and wishes of the group participants, which allowed the caring team to modify the programme to meet the needs of these family members. Still, this specific support group programme will not be appropriate for all family members. Some will prefer an individual one-to-one intervention, while others would prefer phone or videophone conversations, and others still would like to take part in web-based support. In an ideal world, a variety of interventions would be offered within standard palliative care, and family members would be given the opportunity to choose when, how, in what way, and for how long they should be supported in handling their caregiving situation. However, being realistic, this vision might be hard to achieve. Finally, it should be noted that not everyone involved in caregiving will be burdened by this role, but some will. To ensure appropriate use of limited resources, health professionals need methods of identifying those family members who may be at increased risk of exhibiting negative consequences and decreased wellbeing during and after a period of caring for someone close to them. Family members’ needs should be assessed regularly during the caring period; appropriate instruments for this might include the Preparedness for Caregiving scale, the Caregiver Competence Scale, and the Rewards of Caregiving Scale. The scales can be used not only for assessing needs but also to evaluate interventions aimed at meeting these needs.

Acknowledgement

As I write this, I am close to finishing my thesis and the feeling is indescribable. It is hard to imagine but I have actually nearly made it! There are so many people who have contributed to this thesis and I would like to express my deepest gratitude to all of you. Special consideration goes to the following:

First I am sincerely grateful to all the family members who agreed to participate in the studies. Without your generosity it would not have been possible to write this thesis. Thanks also to all the health professionals at the four study settings. A special thanks to the group leaders in the intervention settings— you are so great! Keep up your excellent work in supporting family members.

Professor Birgitta Andershed, my main supervisor and my scientific mum! You have gently guided me from the start of my research journey. Thank you for always being there for me in good times and in bad. No one could have supported me better in this than you did. I have felt so safe knowing I could always lean on you. Thank you for sharing your research skills and experiences, encouraging and inspiring me to keep going.

Professor Britt-Marie Ternestedt, my co-supervisor and my role model! Do I need to say more? Thank you for sharing all your research skills and experiences, and your wisdom about life. Thanks also for giving me such a lovely workplace at the Department of Palliative Care Research. I have enjoyed it so much and you made me feel at home from the first day.

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PhD Kristoffer Årestedt, my co-author. What would I have done without you? There are not words enough to describe all your qualifications. You are simply the best.

PhD Berit Seiger Cronfalk, my mentor and friend. Thank you for all your support, for giving me your full attention, and for sharing your experiences. I have really appreciated our mentor meetings.
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### Svensk version av Preparedness for Caregiving Scale

Följande frågor handlar om hur förberedd du känner dig för att våra din närstående. Sätt en kryss i den ruta som överensstämmer med dina upplevelser.

<table>
<thead>
<tr>
<th>Inte förberedd alls</th>
<th>Ganska dåligt förberedd</th>
<th>Till viss del förberedd</th>
<th>Väl förberedd</th>
<th>Mycket väl förberedd</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Hur väl förberedd tror du att du är för tillgodose din närståendes fysiska behov?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Hur väl förberedd tror du att du är för att möta din närståendes känslomässiga behov?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Hur väl förberedd tror du att du är för att identifiera hjälpbehov hos din närstående och att hitta lösningar?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Hur väl förberedd tror du att du är inför den påfrestning som vårdandet medför?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Hur väl förberedd tror du att du är för att göra vårdandet så bra som möjligt för både dig själv och din närstående?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Hur väl förberedd tror du att du är på att hantera akuta situationer som rör din närstående?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Hur väl förberedd tror du att du är för att hitta hjälp och information du behöver från hälso- och sjukvården?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Generellt sett, hur väl förberedd tror du att du är för att våra din närstående?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Stewart & Archbold (1986, 1994)
Svensk version Henriksson et al. (2011)
**Svensk version av Caregiver Competence Scale**
Följande frågor handlar om hur kompetent du känner dig som vårdare. Sätt ett kryss i den ruta som bäst överensstämmer med dina upplevelser:

<table>
<thead>
<tr>
<th>I vilken grad:</th>
<th>Inte alls</th>
<th>Lite</th>
<th>Ganska mycket</th>
<th>Mycket</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 - Troar du att du lärt dig att hantera mycket svåra situationer?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 - Känner du att du på det hela taget är en bra vårdare?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Tänk nu på de dagliga upp och nedgångar som du möter som vårdare: arbetet du utför och det sätt du hanterar svårigheter. Om du väger samman dessa saker:

<table>
<thead>
<tr>
<th>I vilken grad:</th>
<th>Inte alls</th>
<th>Lite</th>
<th>Ganska mycket</th>
<th>Mycket</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 - Känner du dig kompetent?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 - Känner du tillit till dig själv?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Pearlin (1990)
Svensk version Henriksson et al. (2011)
Svensk version av Rewards of Caregiving Scale
Följande frågor handlar om den eventuella personliga behållning vårdandet ger dig. Sätt ett kryss i den ruta som bäst överensstämmer med dina upplevelser.

<table>
<thead>
<tr>
<th>Inte alls</th>
<th>Ganska lite</th>
<th>Något</th>
<th>Ganska mycket</th>
<th>Mycket</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Bidrar vårdandet till en känsla av att du gör något viktigt?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 Bidrar vårdandet till att du känner dig röjd med dig själv?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Är vårdandet givande genom att du gör livet lite lättare för din närstående?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 Tillhör vårdandet mening i ditt liv?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 Bidrar vårdandet till en känsla av att du utför något betydelsefullt?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 Är det givande för dig att &quot;bara finns där&quot; för honom/henne?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Inte alls</td>
<td>Ganska lite</td>
<td>Något</td>
<td>Ganska mycket</td>
</tr>
<tr>
<td>---</td>
<td>-----------</td>
<td>-------------</td>
<td>-------</td>
<td>---------------</td>
</tr>
<tr>
<td>7</td>
<td>Medför vårdandet personlig utveckling för dig?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Är du glad att det är just du som värderar honom/ henne?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Är vårdandet givande eftersom det gör din närstående glad?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Är det givande att veta att du är till hjälp för honom/ henne?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Stewart & Archbold (1986, 1993)
Svensk version Henriksson et al. (2011)
Svensk version av Herth Hope Index (HHI-S).

Nedan återfinns ett antal påståenden. Läs varje påstående och sätt ett kryss (x) i rutan som beskriver hur mycket du håller med det påståendet just nu.

<table>
<thead>
<tr>
<th></th>
<th>Stämmer inte alls</th>
<th>Håller inte med</th>
<th>Håller med</th>
<th>Instämmer helt</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Jag ser positivt på livet</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>Jag har kortsiktiga och/eller långsiktiga mål</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>Jag känner mig alldeles ensam</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>4.</td>
<td>Jag kan se ljuset i tunneln</td>
<td></td>
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<tr>
<td>5.</td>
<td>Jag har tro som ger mig tröst</td>
<td></td>
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</tr>
<tr>
<td>6.</td>
<td>Jag känner mig rädd inför min framtid</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>7.</td>
<td>Jag kan erinra mig minnen från glada/lyckliga tider</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>8.</td>
<td>Jag har djup inre styrka</td>
<td></td>
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</tr>
<tr>
<td>9.</td>
<td>Jag kan ge och ta emot ömhet/kärlek</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>10.</td>
<td>Jag vet vart jag är på väg</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td>Jag tror att varje dag har något att ge</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>12.</td>
<td>Jag känner att mitt liv har ett värde</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

Kaye Herth (1989)

<table>
<thead>
<tr>
<th>Fråga</th>
<th>Alternativ</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Jag känner mig spänd eller &quot;uppskruvat&quot;</td>
<td>○ För det mesta</td>
</tr>
<tr>
<td></td>
<td>○ Ofta</td>
</tr>
<tr>
<td></td>
<td>○ Då och då</td>
</tr>
<tr>
<td></td>
<td>○ Inte alls</td>
</tr>
<tr>
<td>2. Jag uppskattar samma saker som förut</td>
<td>○ Precis lika mycket</td>
</tr>
<tr>
<td></td>
<td>○ Inte lika mycket</td>
</tr>
<tr>
<td></td>
<td>○ Bara lite</td>
</tr>
<tr>
<td></td>
<td>○ Knappast alls</td>
</tr>
<tr>
<td>3. Jag får en slags känsla av rådsla som om någonting förfarligt hänger på att hända</td>
<td>○ Alldeles bestämt och rätt illa</td>
</tr>
<tr>
<td></td>
<td>○ Ja, men inte så illa</td>
</tr>
<tr>
<td></td>
<td>○ Lite, men det oror jag inte</td>
</tr>
<tr>
<td></td>
<td>○ Inte alls</td>
</tr>
<tr>
<td>4. Jag kan skratta och se saker från den humoristiska sidan</td>
<td>○ Lika mycket som jag alltid kunnat</td>
</tr>
<tr>
<td></td>
<td>○ Inte riktigt lika mycket nu</td>
</tr>
<tr>
<td></td>
<td>○ Absolut inte så mycket nu</td>
</tr>
<tr>
<td></td>
<td>○ Inte alls</td>
</tr>
<tr>
<td>5. Oroande tankar kommer för mig</td>
<td>○ Mycket ofta</td>
</tr>
<tr>
<td></td>
<td>○ Ofta</td>
</tr>
<tr>
<td></td>
<td>○ Ja och då men inte så ofta</td>
</tr>
<tr>
<td></td>
<td>○ Bara någon ensak gång</td>
</tr>
<tr>
<td>6. Jag känner mig glad</td>
<td>○ Inte alls</td>
</tr>
<tr>
<td></td>
<td>○ Inte ofta</td>
</tr>
<tr>
<td></td>
<td>○ Ibland</td>
</tr>
<tr>
<td></td>
<td>○ För det mesta</td>
</tr>
<tr>
<td>7. Jag kan sitta i lugn och ro och känna mig avspärd</td>
<td>○ Absolut</td>
</tr>
<tr>
<td></td>
<td>○ Oftast</td>
</tr>
<tr>
<td></td>
<td>○ Inte ofta</td>
</tr>
<tr>
<td></td>
<td>○ Inte alls</td>
</tr>
<tr>
<td>8. Jag känner mig som om jag gick på &quot;lågt varv&quot;</td>
<td>○ Nåstan jämnt</td>
</tr>
<tr>
<td></td>
<td>○ Mycket ofta</td>
</tr>
<tr>
<td></td>
<td>○ Ibland</td>
</tr>
<tr>
<td></td>
<td>○ Inte alls</td>
</tr>
<tr>
<td>9. Jag får en slags känsla av rådsla som om jag hade &quot;järlor i magea&quot;</td>
<td>○ Inte alls</td>
</tr>
<tr>
<td></td>
<td>○ Någon gång</td>
</tr>
<tr>
<td></td>
<td>○ Rätt ofta</td>
</tr>
<tr>
<td></td>
<td>○ Mycket ofta</td>
</tr>
<tr>
<td>10. Jag har tappat intresse för mitt utseende</td>
<td>○ Absolut</td>
</tr>
<tr>
<td></td>
<td>○ Jag bryr mig inte så mycket om det som jag borde</td>
</tr>
<tr>
<td></td>
<td>○ Jag kanske inte bryr mig om det riktigt så mycket</td>
</tr>
<tr>
<td></td>
<td>○ Jag bryr mig precis lika mycket om det som förut</td>
</tr>
<tr>
<td>11. Jag känner mig rastlös som om jag måste vara på spräng</td>
<td>○ Verkligen mycket</td>
</tr>
<tr>
<td></td>
<td>○ En hel del</td>
</tr>
<tr>
<td></td>
<td>○ Inte så mycket</td>
</tr>
<tr>
<td></td>
<td>○ Inte alls</td>
</tr>
<tr>
<td>12. Jag ser fram emot saker och ting med glädje</td>
<td>○ Lika mycket som förut</td>
</tr>
<tr>
<td></td>
<td>○ Något mindre än jag brukade</td>
</tr>
<tr>
<td></td>
<td>○ Kallt mindre än jag brukade</td>
</tr>
<tr>
<td></td>
<td>○ Nästan inte alls</td>
</tr>
<tr>
<td>13. Jag får plötsliga panikkänslor</td>
<td>○ Verkligen ofta</td>
</tr>
<tr>
<td></td>
<td>○ Rätt ofta</td>
</tr>
<tr>
<td></td>
<td>○ Inte så ofta</td>
</tr>
<tr>
<td></td>
<td>○ Inte alls</td>
</tr>
<tr>
<td>14. Jag kan njuta av en bra bok, ett bra radio eller TV-program</td>
<td>○ Ofta</td>
</tr>
<tr>
<td></td>
<td>○ Ibland</td>
</tr>
<tr>
<td></td>
<td>○ Inte så ofta</td>
</tr>
<tr>
<td></td>
<td>○ Mycket sållan</td>
</tr>
</tbody>
</table>


A support group programme  ANETTE HENRIKSSON  | 107
Detta formulär innehåller frågor om hur Du mår. Det finns fyra möjliga svar för varje fråga. Sätt ett kryss i den ruta som bäst beskriver **hur du mätt under veckan som gått**.

Arbeta snabbt och fundera inte länge på någon fråga. Hoppa inte över någon fråga.

1. **Hur är det med din ork?**

<table>
<thead>
<tr>
<th>Orkar ingenting</th>
<th>Orkar ganska lite</th>
<th>Orkar ganska mycket</th>
<th>Orkar nästan hur mycket som helst</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

2. **Hur är det med ditt humör?**

<table>
<thead>
<tr>
<th>Är så ledsen man kan bli</th>
<th>Är ganska ledsen</th>
<th>Är ganska glad</th>
<th>Är så glad man kan bli</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

3. **Hur trött känner du dig?**

<table>
<thead>
<tr>
<th>Mycket trött</th>
<th>Ganska trött</th>
<th>Inte särskilt trött</th>
<th>Inte alls trött</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

4. **Känner du dig ensam och isolerad?**

<table>
<thead>
<tr>
<th>Mycket ensam</th>
<th>Ganska ensam</th>
<th>Inte särskilt ensam</th>
<th>Inte alls ensam</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

5. **Hur är din sömn?**

<table>
<thead>
<tr>
<th>Sover mycket dåligt</th>
<th>Sover ganska dåligt</th>
<th>Sover ganska bra</th>
<th>Sover mycket bra</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

6. **Har du yrsel?**

<table>
<thead>
<tr>
<th>Har ständig yrsel</th>
<th>Har ofta yrsel</th>
<th>Har sällan yrsel</th>
<th>Har aldrig yrsel</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>
7. Hur tycker du att din mage fungerar?

<table>
<thead>
<tr>
<th>Har mycket besvär med magen</th>
<th>Har gansa mycket besvär med magen</th>
<th>Har lite besvär med magen</th>
<th>Har inget besvär alls med magen</th>
</tr>
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<tbody>
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</tbody>
</table>

8. Besväras du av värk eller smärta?

<table>
<thead>
<tr>
<th>Har ständig värk</th>
<th>Har ofta värk</th>
<th>Har sällan värk</th>
<th>Har aldrig värk</th>
</tr>
</thead>
<tbody>
<tr>
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</tbody>
</table>

9. Har du svårt att röra dig?

<table>
<thead>
<tr>
<th>Har mycket svårt att röra mig</th>
<th>Har ganska svårt att röra mig</th>
<th>Har lite svårt att röra mig</th>
<th>År inte alls hindrad</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</table>

10. Hur har din hälsa varit i stort den senaste veckan?

<table>
<thead>
<tr>
<th>Mycket dålig</th>
<th>Ganska dålig</th>
<th>Ganska bra</th>
<th>Mycket bra</th>
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<tbody>
<tr>
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</table>

11. Hur bedömer du ditt allmänna hälsotillstånd?

<table>
<thead>
<tr>
<th>Mycket dålig</th>
<th>Ganska dålig</th>
<th>Ganska bra</th>
<th>Mycket bra</th>
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</thead>
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</tbody>
</table>

Forsberg & Björvell (1993)
   Doktorsavhandling/Doctoral thesis with focus on Nursing.

   Doktorsavhandling/Doctoral thesis with focus on Nursing.

   Vetenskaplig uppsats för licentiatexamen/Academic essay.

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* Seriens namn var tidigare (nr 1–24) ”Örebro Studies in Caring Sciences”.
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   Vetenskaplig uppsats för licentiatexamen/Academic essay.

   Doktorsavhandling/Doctoral thesis with focus on Nursing.

20. Lidskog, Marie (2008) *Learning with, from and about each other: Interprofessional education on a training ward in municipal care for older persons.*
   Doktorsavhandling/Doctoral thesis.

   Doktorsavhandling/Doctoral thesis with focus on Public Health.

   Doktorsavhandling/Doctoral thesis with focus on Nursing.

   Doktorsavhandling/Doctoral thesis with focus on Nursing.


