

Loved ones within palliative care
– understanding, strategies and need for support

Inger Benkel

Institute of Medicine
Department of Public Health and Community Medicine
Geriatric Unit
at Sahlgrenska Academy
University of Gothenburg

© Inger Benkel
Institute of Medicine, Department of Public Health and Community Medicine
Geriatric Unit, at Sahlgrenska Academy
University of Gothenburg

inger.benkel@vgregion.se

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ABSTRACT

It is well known that during the palliative process both patient and loved ones have to face, and prepare themselves, for the patient's approaching death. Their daily life will be marked by the disease, and physical, social, psychological and existential questions will arise.

Increased knowledge about being a loved one involved in palliative care could provide important guidance for the professional staff to enabling them to support the loved ones in finding new ways of living after the patient's death.

The aim of the thesis was to increase knowledge of what it can be to be a loved one involved in palliative care from the perspective of understanding what is going on, strategies used and support needed.

The studies used both qualitative and quantitative methods, in the form of in-depth interviews and questionnaires with open-ended questions. Descriptive statistics and content analysis were used, in the analysis.

The results show that the understanding of loved ones depended on information given in various ways during the disease process. The information could be gained either explicitly from health-care staff or implicitly from everyday conversation between themselves and the patient or throughout the progression of the disease.

The loved ones used different types of strategies to cope with the situation and to be able to meet the patient in the current situation. The professional carers opinion was that the more informed and aware the loved ones were about the patient's disease the more they were able to cope with the situation. Information was helpful both in preparing for and during the bereavement. Need for support after the patient's death, depended on how they managed the bereavement process, together with the kind of relation they had had with the dead person.

The personal network was the most important source of support in contrast to professional support which was mainly needed when the personal network for some reason failed or when the grief became complicated. The professional carers opinion was that they could provide the support the loved ones needed during the patient's hospital stay but rarely after the patient had died.

The healthcare system has to find methods to support the loved ones both during the time of the patient's illness as well as during the bereavement process, for those who need such support.

Keyword: Loved ones, information, communication, strategies

SVENSK SAMMANFATTNING

När en patient får veta att han/hon har en obotlig sjukdom förändras livet för patienten och han/hennes närstående. Vården som tidigare haft bot som mål övergår till att ha en palliativ, lindrande inriktning. Den palliativa vården bygger på en filosofi där man ser att döden är en del av livet och är baserad på fyra hörnstenar; symptomlindring, teamarbete, kommunikation och närståendestöd. Den palliativa tiden indelas i en tidig palliativ fas som kan vara under lång tid, från månader upp till år och en sen palliativ fas som är de närmaste dagarna och veckorna innan dödsfallet. Under den tidiga fasen kan patienten erhålla behandling med läkemedel, cytostatika och strålning i palliativt syfte för att lindra symptom och för att få en god livskvalité samt eventuellt förlänga livet. I den sena fasen är inriktningen på vården att ha god symptomlindring. Under sjukdomstiden kan frågor av fysisk, psykisk, social och existentiell karaktär väckas och som de närstående kan ha behov av att samtala omkring och de behöver finna vägar att hantera den nya livssituation som har uppkommit. Efter dödsfallet kommer de närstående att genomgå en sorgprocess, som ska ge dem möjlighet att finna sitt egna liv utan att patienten längre finns i livet.

Avhandlingens syfte var att undersöka hur de närståendes process till insikt om att patient kommer att dö ser ut, hur de får information om sjukdomen och hur de hanterar livet under patientens sjukdomstid. Ett annat syfte var att undersöka vem som ger stöd och vilken form av stöd de närstående behöver i sorgprocessen efter patientens död. Deltagarna i studierna var närstående till patienter som avlidit på den palliativa enheten samt inom de geriatriska, onkologiska och urologiska klinikerna på Sahlgrenska Universitetssjukhuset i Göteborg. Djupintervjuer med närstående var den huvudsakliga metoden som användes samt några olika enkäter. I intervjuerna fick de närstående beskriva sina upplevelser både under sjukdomstiden och hur de upplevde sorgprocessen efter att patienten hade avlidit. Intervjuerna skrevs ut ordagrant och analyserades med en sk innehållsanalys, vilket innebär att man ser om det fanns likheter i de närståendes sätt att förhålla sig till sin situation, som närstående till en svårt sjuk patient och vem som gav dem stöd under sorgprocessen. För att ytterligare se vilket stöd de närstående erhöll under sorgprocessen fick de besvara en enkät med öppna frågor. Enkätsvaren jämfördes med innehållet i intervjuerna. En annan enkät användes för att de närstående skulle uppskatta om de uppfattade att de hade en känsla av sammanhang i den situation de befann sig i.

Personalen på de berörda klinikerna fick besvara en speciell enkät där de skulle bedöma hur de upplevde att närstående kunde förstå och hantera sin situation samt vilket stöd de uppfattat att de närstående behövde.

Enkäterna har bearbetats statistiskt med frekvenser och procenttal.

Resultatet i studierna visade att det fanns olika sätt att hantera sorgeprocessen för att kunna anpassa sig till det nya liv, när den som dött inte längre fanns i livet. De kunde beskrivas inom fyra områden. Dels var det att kunna ta paus från sorgen vilket innebar att man tänkte på eller aktiverade sig med annat och la sorgens känslor och tankar åt sidan ett tag. Då fick man kraft att orka de känslor som sorgen väckte. De behövde också kunna göra någon form av avslut eller sammanfattning av den tid de haft tillsammans med patienten. Det innebar att de ska kunna ha patienten i sitt minne, men att det som hänt inte ska försämra det dagliga livet. För att kunna hantera sorgen behövde de närstående förstå vad som hade hänt under sjukdomstiden och varför den som var sjuk dog. Fanns inte förståelsen för vad som föranledde dödsfallet behövdes det redas ut under sorgeprocessen. Det påverkade också hur man hade haft möjlighet att förbereda sig på att dödsfallet skulle komma att ske.

Resultatet visade också att de närstående fick information på olika sätt under hela patientens sjukdomstid. Det kunde ske i form av information som förmedlades genom klara ordalydelser som beskrev sjukdomen och dess konsekvenser. Det var ofta fallet när de närstående talade med sjukvårdens personal. Hur sjukdomen fortskred och symtomen som sjukdomen förorsakade, gav en indirekt information om vad som höll på att hända. Patienten och de närstående kunde tala med varandra om döden i klartext men också genom symboler för det som kändes ångestfullt att tala öppet om. Ett exempel var att tala om döden som skulle komma, genom att berätta om hur man ville ha sin begravning. Det innebar en dubbel information, både att patienten berättade om hur han/hon ville ha det rent praktiskt med begravningen men också som en symbolik i att patienten snart skulle dö. De närstående upplevde att de olika vägar som de fick information på, var en hjälp i att förbereda sig på att patienten skulle komma att dö.

De närstående använde sig av olika strategier för att kunna hantera den uppkomna situationen och kunna bemöta patienten som en levande person. En av de strategier som identifierades var; Att tänka att döden, kommer längre fram vilket innebar att man visste att sjukdomen skulle komma att leda till döden, men eftersom det inte gick att säga när det skulle ske, behövde de inte tänka på det varje dag. Trots det, tänkte de närstående under vissa stunder

ändå på att patienten kommer att dö. En annan strategi var att hoppas på en förbättring. Det innebar att när patienten fick nya symtom av sin sjukdom, smärta, illamående eller liknande, skiljde man dem åt från grundsjukdomen och försökte fokusera på att de var behandlingsbara och hoppas på att patienten skulle kunna bli bättre. Strategin att Leva i nuet innebar att man koncentrerade sig på att hitta ett bra sätt att leva så att sjukdomen störde vardagslivet så lite som möjligt, men ändå anpassa sig efter de nya förutsättningarna. Det var viktigt att upprätthålla de vanliga rutiner som de hade haft tidigare och de aktiviteter som var möjliga, trots sjukdomen. Den sista strategin var Att använda sig av nätverkets strategier är att hantera uppkomna svårigheter som familj/nätverk utformat på ett speciellt sätt under lång tid och som de närstående kände väl till. Då kunde man inom familjen/nätverket göra på det sätt som de lärt sig göra när något allvarligt händer och det blev en hjälp att hantera vardagen.

Personalen skattade att ju mer de närstående var medvetna och informerade om patientens sjukdom, desto bättre kunde de hantera sin situation och förbereda sig på dödsfallet.

Personalen på sjukhuset ansåg att de kunde ge det stöd som de närstående behövde den tid patienten vistades på sjukhuset, men att det var sällsynt att de kunde ge stöd till de närstående efter att patienten hade dött.

Vilken relation de närstående hade till patienten såväl som hur de hanterade sorgprocessen, påverkade vilket stöd de närstående behövde i sorgen efter att patienten hade dött. Relationen berodde både på vem det var som hade dött, var i livscykeln de befann sig och vad den döde personen hade betytt, både emotionellt och rent praktiskt i dagliga livet. Resultatet visade att det egna nätverket till största delen kunde ge det stöd som den närstående behövde i sorgen. När nätverket inte kunde ge tillräckligt med stöd, när den sörjande ville skona dem eller när sorgen blev komplicerad kunde den sörjande behöva stöd av professionell personal.

Det är en sårbar tidsperiod för närstående att följa en patient fram till döden och de närstående kan ha behov av olika former av stöd under patientens sjukdomstid liksom under sorgprocessen efter dödsfallet. Hälso- och Sjukvården behöver utarbeta metoder för att identifiera de närstående som har behov av stöd från professionell personal, både under patientens sjukdomstid och i sorgen när patienten har dött.

ORIGINAL ARTICLES

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

- I Benkel I, Wijk H, Molander U. **Managing Grief and Relationship Roles Influences Which Forms of Social Support the Bereaved Needs.** *American Journal of Hospice and Palliative Care.* 2009;26:241 -245.
- II Benkel I, Wijk H, Molander U. **How loved ones obtain information about the progress of the patient's cancer disease is important for their understanding .** *Submitted.*
- III Benkel I, Wijk H, Molander U. **Using Coping Strategies Is Not Denial: Helping Loved Ones Adjust to Living with a Patient with a Palliative Diagnosis.** *Journal of Palliative Medicine.* 2010;1:1119-1123.
- IV Benkel I, Wijk H, Molander U. **Hospital staff's opinions concerning loved ones' understanding of the patient's disease and need for support.** *Submitted*
- V Benkel I, Wijk H, Molander U. **Family and friends provide most social support for the bereaved.** *Palliative Medicine.*2009;23:141-149.

ABBREVIATIONS

SOC Sense of Coherence

WHO World Health Organization

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INTRODUCTION

For many years I have worked as a social worker, in an emergency ward, at a surgery clinic and in a palliative unit. During these years I have met many family members and other loved ones who have lost a dear one. Unexpected loss was caused by accident or unknown disease but death also resulted from a mortal disease, where the diagnosis had been known for a shorter or longer time. Over the years I have followed some loved ones during the patient's disease and have had a follow-up routine after the patient's death. The meaning behind this contact was to offer support if the grieving person needed it. My experience was that most of those grieving drew their support from their personal network and that contact with the hospital staff was only needed in special situations and over a shorter time, but a few people needed support from professionals for a longer time. Since opinions differ concerning whether or not a grieving person needs a contact outside their personal network, I was curious and thought that this could be investigated. So I started the path that led to this thesis. At first my knowledge was experience based but during my research I have learned a lot and it has given me a deeper knowledge about how the loved ones gain insight during the disease process and about the bereavement and social support needed after death. Other questions that arose were how the loved one prepared themselves for the approaching death during the patient's disease and how they managed such a situation.

BACKGROUND.

When curative treatment is no longer available, palliative care can be offered to the dying patient. The patient, as well as his/her loved ones has to face and prepare themselves for approaching death. For a person being diagnosed with an incurable disease, it means that he/she has to make a transition from a healthy life to an existence with physical unhealthy and where life has a known terminal point but don't know when it will be (1). It can be substantial changes in the patients' and loved ones lives, from mental, physical and practical view(2) and a new life situation raises questions not only about physical, social, psychological and but also of existential character (3).

When a person is faced with a crisis, such as being diagnosed as having an incurable disease, he/she uses strategies in order to cope and to find some coherence in the situation (4). For loved ones there is a bereavement period after someone close to them has died, which gives them the possibility of arranging their future life without the patient's presence and of finding a new way of living (5).

This thesis focused on the loved ones, in connection with the patient. They have had a life together and they are important to each other and influence each other's ways of thinking, reacting and acting, especially during the disease but also through their memories in the bereavement period.

Definition of loved ones

Earlier the family has been seen as an inner circle of husband, wife and children, maybe including the older generation in the same area. The family is like a system with different relations, communication patterns, process and structure factors among the members and all influence how those within the system function and cooperate (6). However in the western countries over the last few decades the concept of the family as comprising those closest to someone has changed and is now, much wider and includes many different constructions (7). Families nowadays can be more like a network with a variety of relationship and generations (8). This development has given rise to a wider understanding of who can be considered close to the patient and it has therefore been more common to use the word loved ones to describe those whom the patient designates as being close. A loved one can be someone in the closest family, the initial family, an earlier family member, a friend or someone else. The important

thing about being a loved one is that the patient chose this person to be close to her/him whatever their affinity (9).

Palliative Care

Palliative care is a movement that was started in England by Dame Cicely Saunders at St Christopher's Hospital in the 1960s (10). World Health Organization's,(WHO's) definition of palliative care guides palliative care in all countries (11). Palliative care is built on a philosophy which sees dying as a natural part of life and its purposes are to aim for the highest possible quality of life for the patient. It is an interdisciplinary care, based on communication and provide symptom control from physical, psychological, social and existential perspectives. Palliative care should also provide support for the loved ones in their grieving process (12,13,14,15). Sandman has described some of the ethical aspects of palliative care, which can be important considering the dilemmas which can arise during the illness process (16). In order to help the patient and the loved ones with all such questions the palliative team has to include different professionals (17).

The palliative period starts when a disease is diagnosed as incurable and the treatment prescribed palliative care. It can last for a shorter or a longer period, depending on how the disease develops. Palliative care is divided into the early palliative period, which can last for several months or years, when the purpose is to prolong life and afford a high quality of life with good symptom control. Once the disease has developed and death is expected within a few weeks or days, late palliative phase begins. The purpose of treatment in this phase is to have high quality symptom control (15). Palliative care can also take a health promoting perspective which includes social support, support in daily life matters, giving information and educating about health, death and dying (18,19). Basic palliative care is performed in all contexts in the health care system and requires a certain but limited amount of competence among the staff in contrast to the specific competence needed within specialist palliative care performed at palliative care units and hospices (20).

Being a loved one during the patient's illness process

During the period of illness of a life-threatening disease the contact between the loved ones and the patient can be close or distant, depending on their relationship (9). The patient is always in focus and the one who decide how much the loved one should be involved, both in terms of daily life and in knowledge about the course of the disease. Both patient and loved

one have to face the reality of the illness, but can use different strategies in order to manage the daily life. How these strategies manifested is individual and can never really be predicted. Everyone has their own way of using coping strategies to regain a sense of equilibrium and to manage daily life (4,21,22).

Loved one and patient have to create a new pattern for daily life. It can influence the loved ones psychological and physical health and can also lead to changes in relationship and personality as well as other functions (23,24,25). The loved ones can be carers for the patient, meaning that they live close together in new circumstances in the presence of an incurable disease (26,27). They can try to be strong and positive and to live as normal a life as possible (28). There are positive effects for the loved ones in personal growth deriving from caring for someone close, and despite the necessity and adversity the loved ones can be proud of having been helpful to the patient. The cooperation between patient and loved ones can also be highly valued (21,28). Hope will help both the patient and the loved one during this time.

Definitions of hope vary but it generally includes a positive orientation towards the future (29). But the loved ones are vulnerable because they have to hold the balance between burden and capacity, in their need to raise the quality of life (30,31,32).

Both the patient and the loved ones may have time to prepare for the approaching death, knowing what is going to happen, as well as planning for the death. This can begin a form of anticipatory grief for the loved ones, already experienced during the patient's illness and this type of grieving is like a preparation for what the coming grief is going to feel like and how life will be changed (33). Preparedness can be helpful in the grief coming to the loved ones (34) and Valdimarsdottir (35) has identified the need for an awareness time of 3 – 6 month in order to reach an intellectual understanding of what is going to happen.

The bereavement process

When someone has died bereavement time follows for the loved ones. Grief is the process of psychological, social and somatic reactions to the perception of loss (36). The theoretical framework for bereavement can be found in the chapter about theory of bereavement. Grief is like a process and is individual, varying from a strong, traumatic, crisis reaction to calm acceptance, and cannot be predicted (37,38,39). It contains sadness but also times when the grieving person manages daily life as before the loss. Memories of the deceased will be a part of the bereaved inner self, but should not be a feeling of constant pain (5). Grief can influence the grieving person's quality of life and is can be one of life's most stressful events

(40,41,42). Gilles et al(43) see grief as a critical process and find it necessary for the grieving person to find a sense of understanding identified by Antonovsky as a sense of coherence (44). The purpose of the grieving process is to incorporate the loss into the inner self, the dead person has to exist in the memory and the incident has to be a part of life, like an internal scar that does not hurt every day. Grief also depends on who was dying and what possibility there was of being prepared in an anticipatory grief, as seen other studies (33,34,45). How the dead person was treated can also influence the loved ones' bereavement (46). Bonanno has pointed out that *resilience* is a way of maintaining equilibrium as opposed to *recovery* where the function temporarily is lower and there is a gradual return to the pre-event level (47).

Grief can be normal or complicated but most people have a normal bereavement (48). Sometimes it can be difficult to separate complicated grief from a bereavement-related depression as a normal grief includes feelings of depression. Complicated grief is a longer process which needs special treatment (49,50,51,52,53). There are many factors that influence bereavement outcome, such as age, gender, physical disorder, dealing with care giving, loss of a child, attachment in childhood and strategies for coping with the bereavement (38,40,54,55,56,57,58).

Some studies point out that social support in a grieving process can be a protecting against an adverse outcome, both physical and mental (59,60,61).

THEORETIC FRAMEWORK

Grief, Bereavement and Mourning

In the English language grief is the emotional reaction to the loss of someone close, bereavement is the state a person is in after the loss and mourning is the social and cultural expression of grief.

Grief has usually been defined from different psychological perspectives during the 20th century. Freud (62) saw grief from the psychoanalytical perspective believing that grief is a painful reaction to the loss of a person and that the purpose of bereavement is to withdraw the love for and the bond to the missing person. In line with Freud's psychoanalytical explanations, Erich Lindemann (63) identified grief as both a somatic and psychological reaction. He described a normal grieving process as divided into different phases helping to emancipate the survivor from bondage to the deceased. If the grieving person does not go through this process, their grief can be transformed into a morbid grief. Lindemann also identified an anticipatory grief which is when a person experiences a grieving process before the sick person is dead. In his article from 1961 "Process of mourning" (64) John Bowlby also described grieving as a psychological process, advancing in phases, helping the grieving person to withdraw their emotions from the deceased and give them an opportunity to develop a new relationship with someone else. If the bereavement does not follow the normal process, it can turn into pathological mourning.

Late in the 20th century a new paradigm was introduced by Silverman, Steven and Nickman called Continuing Bonds. (65) The process has no end but instead continues with stronger feelings and sorrow, especially during the first year which increasingly decline as the relationship consigned to the past. They believe that a grieving person remains connected to the deceased through an inner representation. If the bonds have a bad influence the grieving process is unhealthy for the grieving person. Valentine describes how a grieving person builds a grief narrative, which giving a remembered relationship with the deceased (66). Wortman and Silver examined the myths that predominate in the research. They have pointed out that the variables for identifying whether the grief is going to be healthy or complicated have not basis in the research.(67)

In Sweden a traumatic crisis has been equated with a grieving process as described by Cullberg (68,69). He stated that traumatic crises arise when an individual is not able to use earlier patterns and strategies in order to manage events. Cullberg, however, has a special

definition of grieving as a painful experience after loss with the purpose of which is to abandon dependence of what is lost. Grief should reduce after a while but can return in the shape of sad thoughts. If a traumatic crises arise because someone has died, the crises and the grief can be attached to each other. At the start of the 21th century Gurly Fyhr (5) separated the grieving process from the traumatic crisis especially in the case of an expected death. She regards grief as a natural part of life that the grieving process should heal psychological wounds and is dependent on how the death occurred. She explains the grieving as a process with different stages. When grief is hidden in the inner self, it can rise up later as a “frozen grief”, in the form of depression or some other form of psychological ill health.

Anticipatory grief is grieving for a future loss. Both Rando (36), Lindemann (63) Simon (33) saw this as a preparation of the approaching grief and is seen when the death is expected. Anticipatory grief can be helpful preparing for the future loss. Rando divided this grief into different stages. If anticipatory grief is too strong, it can have the consequence that the grieving person treats the dying person as if he/she is already dead.

Coping strategies

Coping is defined as the way an individual handles stressful and emotional situations. Folkman et al (4) stated that it includes the thoughts and actions people use to handling stressful event and is both a behavior and a cognitive way of thinking and coping. Coping strategies can be seen as a style or a process that does not have one truth, but is more like a different way of handle the situation. It is not always possible to classify what demands an event is going to make a person to use strategies, this can vary from one person to another. In order to understand whether a person is using coping strategies, three questions are useful (70): *What kind of situation is the person trying to manage? What is the person thinking and doing compared to their ordinary way of thinking and acting? and How have their thoughts and actions changed?* Enander has provided further explanations of the aim in using coping strategies, which is to try to change the situation through concentrating on how to change the problems or to try to change the feelings that the event causes (71). Coping strategies have positive affects regarding handling difficulties and stress (72). There are some specific strategies identified as being used in connection with illness and bereavement. A strategy known as the creative illusion, means that one talks about the reality the way one wants it to be, at the same time as one is well aware of the process of the disease. This is common among cancer patients and their loved ones, with the purpose of the creative illusion to allow them to

act as if the sick person will live for a long time even though they know that their sick family member soon is going to die (73). Grbich et al (22) saw how family members of terminally ill cancer patients used special strategies, for example maintaining previous interests and taking short breaks. Folkman had described that taking time-out and do positive things is helping in the bereavement (72) and Hegge (74) identified attributes such as energy, faith, determination and the support from the network, in coping on widowed elderly people. Stroebe and Shut have in a review article described the dual process model as a way of coping through confrontation and avoidance of the loss (75). Shut (76) and Bennett (77) have seen different strategies used by men and women, while Hearth (78) could not identify any gender differences. Gass (79) found other aspects such as physiological and physical health influence the choice of strategies. Consolation is another form of coping, closely connected to bereavement. Consolation is when you share your experience and feelings with someone else and it exists in the meeting between persons where it mediates strong feelings with no concept or special words. Consolation can consist of several parts and a person must be ready to receive consolation, otherwise it will not help (80).

Social support

Early research into social support starts in the 1970s mostly carried out by American researcher. Cobb defined a buffer hypothesis of buffer, which meaning that social support made it easier to manage crises and had a favourable effect on physical and the psychiatric health.(81) Cassel also showed that the endocrine balance in the human body affects psychosocial processes and can increase disease receptivity (82).

One definition of what social support is describes it as consisting of three dimensions: The relations within a network; the actions performed to give support; and subjective experience of whether the support is helping. These are linked together in a dynamic process between the needed person and the person given the support (82). It seems easier to give access to support if there is a reason why the person needs support, for example after a death (59,83). Social support can influence health and the interventions include element of education and understanding (60,84). Social support after death is described as a special form of support. In general according to Dyregrov the form of social support a bereaved person needs varies and how the need is provided differs as it differs if the bereaved has had to ask for support. Social support can also vary as regards how the bereaved estimated the helpfulness of the support and Dyregrov also stated that social support is mostly given by close family and friend (61).

This is in line with the experience of many Swedes after the Tsunami disaster of 2004 investigated by Berg et al (85). Social support from the network or bereavement support is judged as sufficient in normal grief (59,86). Support can be provided in a variety of ways, for example by telephone, (87) or through IT,(88) which has been developed further nowadays through blogs and bereavements sites An internet self-help intervention has been tested in helping a person with a risk profile for complicated grief, but the method is not yet sufficiently evaluated and more research about such forms of support is needed (89). Other social activities (90), such as activity within their social environment, and self-help groups, can strengthen some bereaves in the ability to cope with the bereavement. Grief counselling and therapy given by professionals may be needed by those with a complicated grief when the social network support not is enough. The risk factors for suffering a complicated grief can be the cause of death, multiple losses, the survivor's health before the loss (91,92).

Different forms of social support can be defined: *Emotional support*, which is when feelings can be expressed to someone who listens; *Network support* is being allowed to participate in a network community and activities; *Cognitive support* is advice, information and guidance; *Practical help* is help with some practical measures; *Instrumental support* is practical help which simultaneously teaches the person how to do it by themselves in the future (60,82).

Sense of Coherence

“Sense of Coherence”- SOC as defined by Aaron Antonovsky (44) has a salutogenic perspective and is focused on health. The salutogenic perspective finds and points out what strengthens health, not what causes illness and is a method for measuring wellbeing. He found explanations of why people manage life situations and crisis so differently when exposed to stress factors. A person has different resistant resources to help him/her to manage and understand what is happening and to give it a meaningful coherence. This process continues throughout life.

SOC includes three concepts; Comprehensibility, Manageability and Meaningfulness

Comprehensibility is *I know* and understand what has happened even if it is a crisis event.

Manageability is *I can* manage the problems and I know the resources I can use, my own or others.

Meaningfulness is *I want* to see what is important in life and can see the meaning of what is happening and I can get through it with my dignity and self-esteem intact (93).

SOC is measured in a questionnaire which assigns numerical values. A high score means high

levels of comprehensibility, manageability and meaningfulness. There are two questionnaires, one with 39 questions and one with 13 questions. Both can be used and giving similar result. The questions have 7 alternative responses but a high score on one question will not always indicate a high SOC value. To estimate whether a person has a feeling of coherence the measure is compared to others in the examined group in similar and special situations. Their total value is divided by number of participants, giving a mean value. This mean value is compared with the person's own value thus measuring if they have a low or a high SOC value. The value does not represent a total truth but rather a tendency regarding how the person feels in the situation at the moment.

Erikson and Lindström (94) have investigated the use of SOC scales and conclude that they cannot measure health in general. A screening scale to identify those heading for ill health is not enough and, they recommend to development of qualitative methods to strengthening the results obtained from the SOC:s scale.

AIM

The aim of the thesis was to increase the knowledge concerning what it can be like to be a loved one involved in palliative care in terms of understanding what is going on, strategies used and support needed.

Specific aims of the paper

The bereavement process is influenced by events during the patient's illness and the need for support after death. (Paper I)

Paper I: To examine what influences the individual's grieving process and the need for support after the patient's death (Study 1).

The loved one's progression towards insight when a patient is dying (Papers II and III)

Paper II: To examine how the loved ones receive information about the progress of the disease that helps them to understand, realize and be prepared for the patient's approaching death (Study 2).

Paper III: To increase knowledge concerning the forms of strategies the loved ones use when they are in the situation of having a dear one with an incurable cancer disease (Study 2)

The professional carers estimation of the loved ones' understanding and support (Paper IV)

Paper IV: To investigate how nurses, assistant nurses and doctors evaluate the loved ones' understanding of the patient's condition and how they assessed the need for support both during hospitalization and after the patient's death (Study 3).

Social support the loved ones need after the patient has died. (Paper V).

Paper V: To increase knowledge concerning the needs for, wishes about, access to and effects of social support during bereavement (Study1).

MATERIAL AND METHODS

Study Design

This thesis is a survey combining qualitative and quantitative approaches. Study 1 used both multi-methods and mixed-methods for the reason of both describing the forms of support provided and to investigate whether the needs for social support were met and how such support could be optimized during the first year of bereavement, on a deeper level (95). Study 1 was divided into three parts (a- c) which made it possible to compare the expectations of social support with the reality of the support received one year later.

Study 2 used a qualitative method to investigate the process towards gaining insight and when the loved one understood that the patient was dying.

In Study 3 had a quantitative method and the professional carers were asked to fill in a questionnaire about the loved ones' understanding that the patient was dying and their need for support during the patient's illness and after the patient's death.

Overview of the studies

Study	Design	Asked participants	Data collection	Method of analysis	Participation n (%)
1a-c	Quantitative and qualitative approach	117 respondents of which 22 in-depth interview	Questionnaires and in-depth interviews	Percentages and frequencies Content analysis	77questionnaire (66%) 13 in-depth interview
2	Qualitative approach	35	In-depth interviews	Content analysis	20 interviews
3	Quantitative approach	343	Questionnaires	Percentages and frequencies	226 (66%)

Settings

The study was conducted at various clinics in Sahlgrenska University Hospital in Gothenburg, Sweden. In Study 1 the participants were loved ones of patients who had died in a palliative care unit in the Geriatric clinic. The participants in Study 2 were loved ones of patients who had died in the Oncology and Urology clinic. In Study 3 the participants were nurses, assistant nurses and doctors working at these three clinics.

Participants

In cases where several family members were eligible for inclusion, a member of the immediate family was given priority. The loved ones thus consisted of spouses, grown up children, brothers, sisters or friends of the patient. No children under 18 were included. In Study 3 all professional carers at the three clinics were invited to participate.

Participant characteristics

In Study 1 almost as many husbands/wives/cohabitants as adult children participated but in the second study there were more husbands and wives. Brothers, sisters, relatives and friends of the deceased took part to a lesser extent. The majority of the respondents were in their mid-50s or older. Most of the participants were employed, a small percent were on sick leave and the remainder were retired. Most of the respondents were living alone at the time of the study. Those who lived with another person were the children of the deceased, parents with small children, and a husband/wife in a new relationship.

Of the participants in Study 1, 33% were males, but only one male agreed to be interviewed. In the second study 16 of those interviewed were women and 4 men; 25 woman and 10 men were asked to participate, 9 of the women and 6 of the men refused to participate. In the third study all staff from the Oncology, Geriatric and Urology clinics was asked to participate. Of the participants 41 % were assistant nurses, 9 % were doctors and 50 % were registered nurse. The majority was aged of 30 – 49 years and there were equal numbers who had worked 1 – 10 years and 11 -30 years. Most of them (80 %) worked days. Men were represented in all professional categories but most of the participants were female.

For further details see Table I –VIII.

Table I: Relationship to the diseased

Study (number)	Husband/wife n (%)	Children n (%)	Brother/sister n (%)	Relative n (%)	Friend n (%)
1 a(n28)	12 (43%)	13(46%)	1 (4%)	2(7%)	
1 b(n27)	12(45%)	12(45%)			3(10%)
1 c(n22)	10(45%)	10(45%)			2(10%)
2 (n20)	11(55%)	7(35%)	1(5%)		1(5%)

Table II: Age of the participants

Study (number)	-50 n (%)	51-64 n (%)	65- n (%)	No answer n (%)
1a (n28)	5 (18%)	15 (54%)	6 (21%)	2 (7%)
1 b (n27)	11 (41%)	12 (45%)	3 (11%)	1 (3%)
1 c (n22)	6 (27%)	11 (50%)	3 (14%)	2 (9%)
2 (n20)	5 (25%)	8 (40%)	7 (35%)	

Table III: Employment

Study (number)	Employed n (%)	Sick leave n (%)	Retired n (%)
1a(n28)	16 (57%)	1 (4%)	11 (39%)
1 b(n27)	17 (63%)	2 (7%)	8 (30%)
1 c(n22)	15 (68%)	1 (5%)	6 (27%)
2 (n20)	11 (55%)	2 (10%)	7 (35%)

Table IV: Civil status and gender

Study (number)	Living alone n(%)	Cohabiting n (%)	No answer n(%)	Female n(%)	Male n(%)
1 a (n28)	12 (43%)	15 (53%)	1(4%)	18 (64%)	10 (36%)
1 b (n27)	16 (59%)	10 (37%)	1 (4%)	17 (63%)	10 (37%)
1 c(n22)	15 (68%)	7 (32%)		16 (73%)	6 (27%)
2 (n20)	10 (50%)	9 (45%)	1 (5%)	16 (80%)	4 (20%)

Study 3**Table V: Participants and gender**

Study 3	Oncology n (%)	Geriatric n (%)	Urology n (%)	Female n (%)	Male n (%)
(n226)	63 (28%)	107(47%)	56(25%)	175 (90 %)	20 (10%)

Table VI: Profession

Study 3	Assistant nurse n (%)	Doctor n (%)	Registered nurse n (%)
(n226)	92 (41%)	21 (9%)	113(50%)

Table VII: Age of participants

Study 3	20-29 n (%)	30-39 n (%)	40-49 n (%)	50-59 n (%)	60- n (%)
(n226)	31 (15%)	52(26%)	59 (29%)	45(22%)	16(8%)

Table VIII: Participants' years of work

Study3	1-10 n(%)	11-20 n(%)	21-30 n(%)	31-40 n(%)	41-50 n(%)	Work day n(%)	Work night n(%)
(n226)	87(41%)	43(20%)	49(23%)	31(15%)	2(1%)	182(80%)	55(24%)

Procedure for data collection**Study 1**

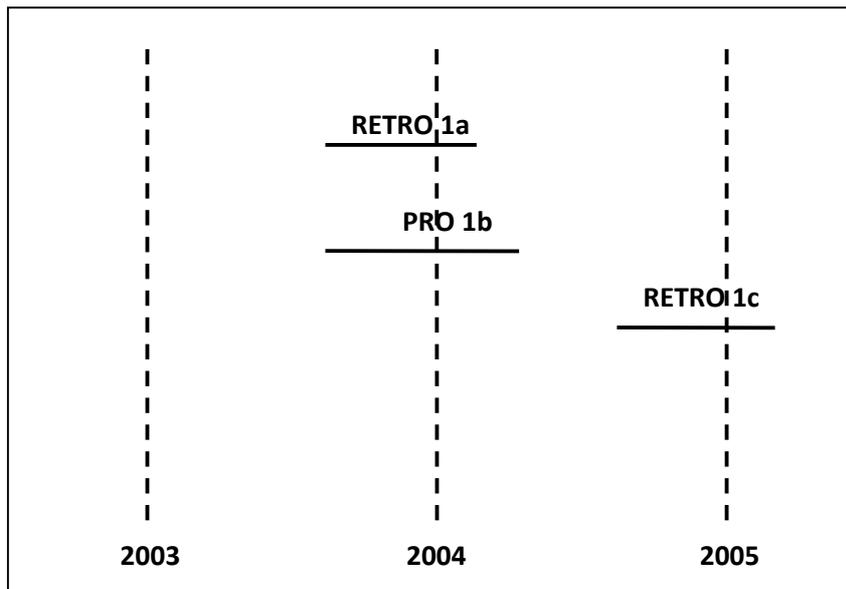
Study 1a started in August 2003 and was finished in January 2004. The study was retrospective and, included 45 consecutive loved ones of patients who had died in the palliative care unit, one year before. Twenty-eight consenting loved ones participated in the study.

Study 1 b was a prospective study and included 45 new consecutive loved ones of patients who had died at the unit 2 months earlier, from August 2003 to March 2004. Twenty-seven loved ones consented to participate in the study. Some loved ones were also asked to participate in a face-to-face in-depth interview with the possibility of only answering the questionnaires if they wished to. Eight loves ones agreed to participate in an in-depth interview. One of them could not be reached at time for the interview thus 7 persons participated at last.

Study 1 c was a retrospective study with the same 27 participants from study 1b. Data were collected one year after study 2, from August 2004 to January 2005. Twenty-two loved ones answered questionnaires and 6 persons agreed to participate in the interviews.

The rate for participated in the quantitative part with questionnaires in study 1 was 66 %.

Data collection period



The social worker in the Palliative Unit contacted the participants by the phone to invite them to participate in the study. Those who agreed were sent a study information letter, a letter of consent and a return envelope. Consenting individuals who decided to participate were sent the semi-structured questionnaires and a questionnaire with the Sense of Coherence Scale, and pre-paid return envelopes to their home address and those participating in the interviews could choose where the interview took place. Participants were guaranteed anonymity.

Study 2

Study 2 included 35 consecutive loved ones, of patients who had died a year earlier in the Oncology clinic in 5 specific months from April 2007 to May 2008 and in the Urology clinic during August and half of September in 2008. The head nurse of the ward and the medical social worker at the clinic telephoned possible participants asking if they would participate in the study. Three people did not want any information at all, which left 32 agreeing to have the information sent by post. They were sent a study information letter, a letter of consent and a pre-paid return envelope and after returning the consent, they were contacted by the investigator to schedule the interview. Twenty loved ones participated in the interviews and could choose where the interview took place anonymously.

Exclusion criteria in study 1 and 2 were psychiatric disease, dementia or unavailability of an interpreter if required. No one was excluded for any of the above reasons. Reasons for not wanting to participate were a wish to avoid talking about what had happened because it hurt

so much. Individuals who could not be reached by telephone or who failed to return questionnaires were considered dropouts.

In all studies those participants who agreed to be interviewed were able to choose where they wanted the interview to take place. The interviews were conducted in the social worker's office, in the participant's own home or in another place which the interviewee chose and some were conducted by telephone.

Study 3

In Study 3 data were collected over three weeks in January and February 2010. Professional carers such as assistant nurses, doctors and registered nurses at the Geriatric, Oncology and Urology clinics were offered the chance to participate by answering a questionnaire estimating the hospital staff's opinions of the loved one's understanding of the patient's disease and their need for support. The participants were asked to participate by the head nurse on the ward and to fill in the questionnaire. The first two weeks were the main period for collecting the questionnaires and the last week was used to remind those who had not returned the questionnaire. The participants left the questionnaire at the ward in a box to ensure anonymity. Three hundred and forty-three persons were asked to participate and 226 did so, i.e. 66%. Reasons for not wanting to participate were not wanting to or forgetting to fill in the questionnaire.

Data Collection Methods

The multi and mixing of methods can be in form of intra-method mixing, which is concurrently used in one study. For example this can include both quantitative and qualitative methods as in using open and closed questions in the same questionnaire. On the other hand methods can be mixed by inter-method mixing which means using questionnaires and some other intervention such as an interview (95). Both interviews and questionnaires were used in these studies. The questionnaire resulted in quantitative data which could be combined with some qualitative data. The variable "comment" and "other" categories allow the participants to give an answer in their own words or provide a concrete example. The interview results is in the form of a report and allows a narrative, when the questions are asked in a specific way (96,97). In Studies 1 a and 3 the questionnaires were the only tool, and in Study 2 only in-

depth interviews were carried out. The SOC questionnaire was assessed using the Sense of Coherence Scale, a standardized, reliable and validated instrument comprising 13 questions (44).

The theory behind qualitative research

Qualitative data is not only a mass of data, it also finds expression of what is important in people's lives. Qualitative research describes a complexity, breadth or a range of occurrences or phenomena (96,97). The use of in-depth interviews and open questions is a way of finding the meaning of the participant's story. It is based on hermeneutic philosophy, described by Heidegger which has its foundation on understanding what something means to a human individual. It also focuses on that the interpretation of what is investigated is circular. This is to compare the parts to the whole and to take in other factors that could be important and a new interpretation is built on the former interpretation. Gadamer introduced the hermeneutic view is given an importance to language in the convey the human process of understanding (98,99). In the research process the researcher must hear what a person says and what this means for the person. Selander believes that hermeneutic thinking is a means to understand and explain the surrounding world regarding social questions, the rules of the life and what the meaningfulness is for the person investigated (100). Everyone including the researcher has a pre-understanding which can influence the interpretation. To "bridling", means that the researcher must not arrive at a quick understanding but must slowly interpret the data, leads to a better chance of being open-minded about what the results really mean (101).

Questionnaires

Four different questionnaires were used in this research. A questionnaire is developed as a self-reported scale and should be clear, have the ability to elicit information, reduce bias and yield sensitive information (102). The questionnaire in Study 1 was developed in cooperation with a professor in Social Work at Gothenburg University, as no existing questionnaire about social support for the bereaved could be found. The questionnaire was tested on colleagues from different professions at the hospital and on the researcher's family members. Some modifications were made in the questionnaires before it was handed out to the participants. In order to have a wide perspective, the questions were designed around how social support was given, the forms of support provided and how such support could be optimized during the first year of bereavement. All questions had several alternative responses and the participants could choose to give more than one answer and comments. Questions about who was

giving/gave social support were particularly frequently given more than one answer. The questionnaires in studies 1 a and 1 c were retrospective in design and in Study 1b the questions asked for answers in the present time. The SOC questionnaire was given 7 values, showing comprehensibility, meaningfulness and manageability. They were scored in a special way, with a different value for each variable in the question (44).

As a literature search failed to find any existing questionnaire aimed at examining hospital staff opinions regarding the loved ones' understanding of the patients' disease and their need for support, the fourth semi-structured questionnaire used in Study 3 was developed by the research group. The questions had several alternative responses and in most cases only one alternative could be chosen. Questions about different forms of support could be answered with more than one alternative in order to broaden the information about the support. The questionnaire was piloted among different professions such as nurses, doctors and social workers, at the hospital and some modifications were made before it was handed out to the participants (102).

Interviews

An interview can differ in character depending on its meaning and purpose. Lants (103) points out, that when the interview is meant to investigate the experience of a phenomenon, an open form gives the interviewer the opportunity to go more deeply into the question in order to gain a wider understanding both of the feelings and the experiences of the interviewee. Kvale (96) states that qualitative interviews are not standardized and can use questions to help develop the knowledge and go more deeply into the question while the interview is ongoing. This does not mean that the whole interview is unprepared, quite the opposite. Such an interview, is prepared regarding method, how to collect the data, through writing or taping, how they are to be analyzed (96). The interview process emphasizes sections that provide feedback and interaction between the interviewer and interviewee. The interviewer must communicate clearly what information is desired and how the interview progresses (104).

During the interview the direct response permits one to understand the respondent's world through the open-ended question. An interview guide is the tool used in interviews as a reminder of the theme the researcher wants data about. It will ensure that the same line of inquiry is pursued with each person interviewed (97).

The interview guide in Study 1 was that the same questions were used in the questionnaire and in the interviews with the participants, in order to allow the participant's to reflect on their answers on a deeper level, focusing on the social support the bereaved needs, how their wish for social support was met, and how such support could be optimized during the first year of bereavement in order to meet the aim of the study. The interviews in Study 2 focused upon the loved one's story of the cause of the disease in order to understand their experience. The study had an interview guide with some key questions that highlighted the purpose of the study. Direct questions from the guide were used to enter more deeply into what the studies aimed out.

The interviews in Studies 1 and 2 were audio-taped and transcribed verbatim after the interview and the transcriptions were subjected to content analysis.

Questions in the interview guide in study 2 are presented as an appendix.

DATA ANALYSIS

Statistical analysis

In the study quantitative data were analyzed through gathering the material using percentages and frequencies and presenting them in tables. The analysis of the SOC scales had a schedule for estimating every question, worked out by Antonovsky. A high score represents a strong Sense of Coherence (44).

In the third study a power analysis was made to ensure sufficient material was available for a statistical analysis. The data were analyzed using descriptive statistics comparing similarities and differences between clinics, professional categories, gender, age and time working in the profession. A Pearson Chi-Square test and a Fischer test were used to determine the associations between the differences that appeared (105).

Content analysis

The interviews from Studies 1 b, 1 c and 2 were analyzed using content analysis. The open-ended questions from the questionnaire were also analyzed in this way.

A content analysis identifies the differences and similarities and finds meaning in the data. Even if this study focuses the manifest level, what is actually said, there are also attempts of interpreting the meaning behind the words, on a more latent level. This is possible through the examination of social communications, in documents or transcripts and conversations in an in-depth interview (106). It also examines the visible, surface content and interpretations of the meaning of the text (107). The analysis has several steps beginning with a reading of the entire text to arrive at an understanding of the whole in relation to the context (97). The text is then analyzed to find those sentences and phrases that contain information which is relevant to the aim of the research. Those are known as meaning units. From the meaning units it is possible to create codes indicating commonalities. These codes can be divided into categories which gives an answer to what is happening and is the manifest content. In the categories one or more themes can be created to describe how this happens and how it is brought about. The theme can thereafter be divided into sub-themes (97,106,107).

Trustworthiness

To ensure trustworthiness and validity in qualitative research many aspects have to be considered. Giacomo has described four important aspects for ensuring credibility(108). The participants must be properly selected and those include must be relevant to the research

question, represent a similar context and from similar circumstances. The data collection methods should be chosen and be appropriate for the research aim and settings. There must be enough comprehensive material to support the observed events. The last aspect is that the data must be analysed using qualitative analysis methods (96,97,108,109,110).

To ensure validity, all those asked to participate in these studies represented a person in a similar context and under similar circumstances i.e. a loved one of a patient who had died at the hospital. The data was collected through in-depth interviews. Descriptive validity (95), refers to ensuring trustworthiness in the result in these studies, meaning that during the collection of data, the interviewer corroborated the description given by participants in order to ensure the accuracy. This was done by having an interview guide containing questions to clarify the participant's opinion and to reduce the influence of the investigator's pre-understanding. The participants meaning, concerning what is being studied, is validated by returning a question to ensure understanding. The in-depth interviews resulted in a rich content, ensured a satisfactory description of the research aim. Despite the variation in age, gender and relationship to the deceased the results had many similarities in all studies (107). All interviews were transcribed verbatim and were analyzed by moving carefully back and forth between the data and the different steps in the analysis. To further validate the findings they have been presented to experienced nurses, doctors and social workers. If any differences appeared they were been discussed and an agreed description was formulated. According to Kvale (96) qualitative research results can be theoretically generalized and discussed in connection to other groups of people in the same circumstances.

ETHICAL CONSIDERATIONS

The Research Ethics Committee at the University of Gothenburg approved the study 1 (S 161-03) and the Regional Ethics Board in Gothenburg approved the second and third studies (680-06).

No written reminder was sent out of respect for the grief of the bereaved. Not wanting to participate in a study of this kind must be accorded respect. Whatever the reason given for not wanting to participate, such as not wanting to be reminded of a phase in the grieving process that has already been left behind, or not wanting to be reminded of or reflect on the time of bereavement, all must be seen as good reasons. The bereavement process is a vulnerable time of life and therefore the decision to participate must be decided by the person without any pressure. Only the loved ones themselves can decide whether they want to confront the feelings and memories which may be reawakened by the questionnaires and interviews.

RESULTS

Main findings

The results show that the bereavement process comprises different ways of managing the grief, influences the need for support and depends on the relation to the dead person (Paper I). It was important for the loved to be informed of the patient's disease to be able to prepare themselves for the patient's death and this information is obtained in variety of ways (Paper II). The loved ones use strategies in order to manage daily life (Paper III). The professionals had the opinion that loved ones mostly understand and can manage the death of the patient and that they can provide support during the patient's disease but rarely after the death (Paper IV). The need for support after the death was mostly provided by the bereaved's personal network but support from professionals was needed when the grief was complicated (PaperV).

Specific findings

Understanding

The way the loved ones were informed depended, on the information was giving during the patient's illness time. The results show that the phenomenon of understanding also depends on how the loved ones understand the information and what strategies they use. In Study 2 the loved ones described their experiences of how they had acquired information both clearly and implicitly in different ways (Paper II). One way was in conversation with the healthcare staff, often directly. " *She (the doctor), said it the first time... that this was a fatal disease.*". But the information could be communicated implicitly by the disease progression itself. When the symptoms of the disease were obvious it was easier to understand the fatality of it, but if there was a period when the patient was asymptomatic the preparedness for the death declined. In Study 3 described in Paper IV most of the carers opinion was that the loved ones often understood that the patient had an incurable disease according to the conversations the carers had with them. There was a difference between the professional categories; 74 % of the nurses answered that the loved ones talked to them about the patients approaching death, compared to 51 % of the assistant nurses and 35 % of the doctors ($p < 0.001$). In the very last phase of the patient's life, when death was imminent, it was very important that the staff continuously kept the loved ones updated regarding medication and care. The majority of the staff in Study 3 (Paper IV) thought that the loved ones fluctuated in their understanding of that the patient was going to die, while the rest of them were of the opinion that the loved

ones were very well informed. The staff meant that the correlation between being aware of the disease and to understand that the patient is going to die, was strong.

Another implicit way of receiving information about the approaching death was when the loved ones talked with the patient about it (Paper II). These conversations could be open but could also be about practical matters such as how the patient wanted to arrange the funeral and what it would be like for them as surviving spouses: *"He told me where he wanted to be buried and where I could find the insurance paper."* *"He talked about his anxiety about this and cried... I think these were his best moments."*

The loved ones described how both professional carers, as well as they themselves used some special words symbolically (Paper II). Some of these words could symbolize both positive and negative things depending on the circumstances. Expressions like "pain" and "metastases" were interpreted to mean that the disease was active and spreading, indicating that the use of this expressions was experienced as communicating which stage of the disease the patient was in. A change in the treatment regimen could raise hope that the patient's condition might have improved, or it could be a reminder of how difficult the symptoms of an incurable illness are to manage. The grave was often used both by the patient and the loved ones to communicate information about death and as a strong symbol for the death itself, as well as for the consequences of death. To use of symbols was a helpful in talking about various matters in a less anxiety- provoking way.

Strategies

During the patient's illness

In Study 2 the loved ones described in the interviews how they used strategies in order to cope with the situation of following a dear one towards death (Paper III). A sense of hope was common to all strategies and the same strategies were used regardless of whether the participants lived with the patient or not. The strategies were categorized into four themes (Paper II).

One theme was thinking that the death is far away in the future. Even if the loved ones understood that the disease was incurable with no fixed date of death, they hide this information about the approaching death deep inside themselves. This means, you have the knowledge, but you do not think about it every day, making it possible to encounter the patient as a living person instead of a dying spouse. As one participant said *"You can never know how long it will take, no one can know that"*. Despite using this strategy the loved ones

still thought about the approaching death and even talked about the death with patient in some way.

The other strategy was hoping for an improvement. As the disease worsened and new symptoms appeared, the loved ones hoped that this was temporary and focused on the symptoms. The symptoms were more interesting and important for the loved one because they could be treated. One participant said: “*I still think that he had had too much morphine, that’s why he became so tired and I thought he will soon be better*”.

When the patient received treatment it strengthened the hope that the disease could be kept quiet and made prolonging life a possibility. “*You have hope all the time.. but sometimes I understood*”. Another phenomenon that helped in using this strategy was previous experience. If the patient had had a similar period with pain and other symptoms earlier and had recovered they thought it could happen again.

It was helpful strategy for the loved to live in the present. That meant trying to continue everyday life with housekeeping, cooking etc. and finding some way of continuing everyday life. For those who had children it was very important to continue the daily routine as far as possible. Continuing daily life gave both the loved one and the patient the feeling that the disease was not influencing them so much.” *We tried to live as normal as usual*”, “*We tried to keep daily life as we had always done*”

The strategy of using the family and personal network concerned how the family had coped with problematic situations earlier in life and their own family pattern was used to manage difficulties in the current situation. This gave them the security of knowing how to deal with the problem and if their communication could include what to talk about, concerning feelings, opinions and fears: “*In our family we have never been open about death, we have more joked about it*”. This coping strategy, however, can vary among families and also among members in the same family.

In Study 3 (Paper IV) most of the professional carers judged that the loved ones could cope with the patient’s approaching death. How the professional carers understand the loved ones coping strategies can also influence what form of support they judged that the loved ones need.

During the bereavement process

The interviews in Study 1 gave a wider description of what the bereavement time can be like. The interviews were carried out 2 months after the patient had died and on the second

interview with the same person one year after the death. The participants narrated their story about the time of bereavement and in the analysis they were able to recognize two categories; Managing the grief and Roles in the relation which was also influenced by the need for support (Paper I). The themes in Managing the grief revealed some important areas for coping with the grief in order to begin a process leading to their new life as a survivor.

The themes were *Take a break*, which means you gave the grief “a rest”, put it to one side for a while. One way was to return to the ordinary routines of life, like work and leisure activities. This made it possible to deal with the emotions when they actually came up.

Being informed was about the information of the consequences of a disease given before death, and was essential for being able to understand what was happening during the disease, and why the person died. After the death they could remember and see the coherence in the information they received when the patient was treated. Important circumstances for feel informed was how the information was presented, the content of the information and the strength and capacity of the loved one to assimilate it.

Being prepared entails both knowing what is going to happen during the course of the illness and that death is approaching. But it is also associated with having been in a similar situation earlier in life, both in terms of illness and death and knowing how to do the practical things that have to be dealt after death.

The last area was *To achieve closure*, not in the meaning of forgetting the deceased person, but letting her/him have a place as a memory. This includes the dead person’s whole life to the point of their death. Closure gives the surviving person an opportunity to look forward and create their own life.

Preparedness as a strategy

In Study 2 the participants said that preparedness was based on current information conveyed by the healthcare staff and on the patient’s health status at the moment (Paper II). It was, therefore, difficult for the loved ones to respond to the questions about whether or not they were prepared for the death or not. Many loved ones felt that they were prepared for what was coming, but they still felt unprepared for the loss: “*Yes we were prepared... but it is still sad. “You can never be fully prepared.”* In Study 3 (Paper IV) most of the professional carers judged that the loved ones could cope with the patient’s approaching death and thought that the loved ones fluctuated in their understanding of that the patient was going to die. Both these circumstances influence the preparedness.

Support

During the illness

The findings in Study 1 about *Being informed* and *Being prepared* and influence the what form of support the loved ones need during the bereavement, are connected with having information about the patient's disease during the patient's illness (Paper I).

Nearly all the professional carers had the opinion that the loved ones' primary need for support were to talk to someone and to receive information in different forms, during the patient's stay at the hospital (Paper IV). Most of the professional carers answered that they could give the support the loved ones needed during the time the patient was being treated in the hospital. Other needs for support were described, such as contact with a social worker, chaplain, doctor, nurse, therapy or help with financial issues. In their conversations with the loved ones the carers could estimate whether they need some special support when patient was in the hospital. In Study 2 many loved ones described their need for support from professionals in form of information. They also described how they talked to others in their network about the disease and the approaching death (Paper II) during the illness, a form of support outside the hospital.

After death

Nearly all the professional carers had also the opinion that the loved ones needed support after the patient had died and the most common need for support was to talk to someone and to have various kinds of information (Paper IV). But the carers said that they were not aware if their clinic did or did not have any follow-up support from hospital staff after the patient had died.

In Study1 (Paper V) the loved ones described the support provided after the patient had died. It was the bereaved person's social network consisting of the immediate family, relatives and friends in various combinations that provided most support. The network gave and could provide the support needed by most of the loved ones but in some circumstances there was a need for support from professionals.

The social support could not really be divided into practical or psychological/social support, they were very close to each other. The combination of practical and psychological/social support was most frequently needed, and also provided, to the bereaved. Practical support was most often given by various family members and relatives, whereas psychological/social support was more often given by close family members and friends.

The practical support concerned matters previously handled by the deceased, for which the respondent now needed to take responsibility and for matters concerning the funeral.

Psychological/social support was characterized by the need to talk to other people during the grieving process and they chose the person they wanted to confer with carefully. They discussed different matters with different people, in order to spare the other person from hearing the same thing again and again and not to burden their network or any one individual too much.

Support from professionals mostly occurred as a complement when the private network was already involved, or when there was dysfunction or when the bereaved lacked a network, especially providing emotional support. Practical professional support mostly concerned funeral arrangement, as well as legal and financial counselling. The psychological/social support from professionals was most needed in the time closest to death to supplement the support the loved ones received from their private network and was in the area of emotional support. To clarify the disease diagnose and progression was important for the bereavement process and for those loved ones having a lack of knowledge medical information was needed (Paper I).

The respondents reported generally good health during the first year of bereavement. Sense of coherence, as assessed with the Sense of Coherence Scale, was generally high in the respondents during a year after the patient's death although some experienced a low point. No relationships could be identified between sense of coherence and either the size or composition of social network, living situation (alone vs. together), or employment status (employed vs. retired). Similarly, no relationship was found among those which sense of coherence decreased during the bereavement year.

The findings from the interviews confirm the picture gained from the questionnaire, i.e. that support for the bereaved is provided from within their social network and what the support consist of.

DISCUSSION

The main purpose of this thesis was to examine what it was like to be a loved one within palliative care. The results show that they obtain information in different ways and use strategies in order to cope with the situation both before the patient's death as well as after, in the bereavement process (Papers I,II,III). The results also show that the professional carers judged the loved ones' level of comprehension in the conversations they had with them. In these conversations and that they could identify those loved ones who needed support and were able to assist them in a professional way (Paper IV). During the bereavement process the loved one's own network provided most social support but in special circumstances there is need for support from professionals (Paper V).

Some aspects of the main findings and how they are interlinked will be discussed, following the result.

Understanding

Paper I points out how important it is for the loved ones to be informed before the death and that this influences the bereavement process after the patient's death. They remembered the information they had received during the disease, which helped them to see coherence in the whole illness time and why the patient died. The information is highly valued by the loved ones as an important support, in form of the discussing the questions about illness and death, as Clayton et al have described (111). Parker et al have shown in a review that the caregivers need information during the whole disease process (112).

The information about the approaching death was obtained in various ways (Paper II). One way is directly, using words clearly in conversations and was common in the talks with the health-care staff. According to Clayton et al(111) both the loved ones and the patients preferred straight information, conveyed with empathy. These conversations are an instrument by means of which the health-care staff can judge whether the loved ones understand the seriousness and consequences of the disease (Paper IV). The loved ones and the patients mostly talked to each other about death. These conversations can cause sadness and anxiety, therefore, as seen in Paper II, unspoken agreements and symbols, containing both words and feelings, give them a chance express difficult thing more easily. Using symbols and metaphors can be helpful and can make it easier to approach an anxiety-provoking subject

(113,114) and were used by the loved ones but also sometimes by the health-care staff. Using symbols, when those talking together have agreed about the symbols meaning, ensures that both parts understand what the conversation is really about, without having to talk about it directly. However, using symbols without there being a shared meaning can be problematic. Unless everyone applies the same meaning to them and interprets the words in the same way, there can be a negative impact on the mutual understanding which can lead to misunderstandings.

Another way to obtain information was from the symptoms during the disease. McPherson et al (115) described how loved ones assess both physical and emotional symptoms, but the emotional symptoms seemed to be more difficult to handle. As long as the symptoms were obvious, it was easier for them to regard the disease as an inevitable process and this is latent information. Asymptomatic periods, when the patient might be better, increased the loved one's feeling of hope that the disease was not life-threatening and the longer those periods are the stronger the feeling that the disease is not active. If the symptoms suddenly appear they can, therefore, be understood as a new disease and that it is the symptoms that are the real problem, not the disease.

Strategies

Even when the loved ones have a good understanding of the seriousness of the disease, they use different kinds of strategies to cope with daily life. This is in line with other findings (21,22,73). Paper III shows that the loved ones use different strategies, which were unique for each person, and allow them to predict each other's state of mind. Thus help them to support each other by being attentive to which particular coping strategy was being used at that moment, as was also seen by Downe-Wamboldt et al(116). Some strategies were more important depending where in the life cycle the patient and the loved ones were. In families with young children it was important to maintain daily routines for the security in daily life. Both patients and their loved ones can use coping strategies that only they, as a unit and within their own network patterns have developed and they understand this well. A strong strategy was also to live in the present and maintain ordinary life as much as possible. Thomas et al (28) find it was important to maximize the sense of having a life carrying on as normal when a family member is seriously ill. The well-known routines allow the loved ones to imagine that life is ongoing, undisturbed by the disease any more than necessary. The strategies maintain a sense of hope which has been described in the review written by Clayton

et al(117). It is important to understand that this sense of hope and the use of strategies are not denial, they coexist with the insight and understanding of what is coming. Rustoen (118) states that hope is important to be able to cope with a life-threatening disease and for the loved ones' strategies. If a person lives all the time in reality they may end in a paralyzed anxiety.

Papers II and IV show that the more the loved ones understand about the disease, the better they understand that the patient is going to die and the more possibility they have to cope with the situation and prepare themselves for the change in their future life, as a survivor.

Information is crucial both for the loved ones' understanding and for their preparedness, the realization that the patient is in fact going to die. To prepare is to think about what their new life situation in the future might be and is an anticipatory grief (36). This preparation is an inner process and includes both the information and the use of strategies in order to help the loved ones to cope with their daily life, as especially Paper I, II and III in this thesis particularly show. Preparation includes a cognitive, emotional and practical dimensions and its importance has been shown in other studies (21,34,119).

Support

The professional carers had the opinion that information was the most important support and expressed the view that they could give this support during the patient's hospital stay.

Nevertheless it can be difficult to talk about these things and how the conversation develops depends on how the professionals have been trained to give bad news. Some feel a lot of stress when discussing these matters. Sivesind has found that nurses felt that discussing physical complaints was easier than talking about issues related to death and dying (120).

Study 3 shows that these conversations were common especially with the nurses and the loved ones in connection with the conversations about the patient's daily conditions. If the professionals can learn to use some strategies in these conversations in order to in to cope with such situations, it will give them more confidence to discuss such questions with the loved ones, as many other have mentioned in various studies (112,121, 122, 123,124). The support given to the loved ones after the patient has died contrasted with the situation during the hospital stay. Although the professionals had the opinion that the need for support was the same for the loved ones as before the patient has died, only a few really provided some form of follow-up activity. In Paper V some of the respondents needed to talk to a doctor after the

death, to deal with medical questions. This indicate that information is crucial both for understanding and for preparedness.

Despite the professional carers seeing the absence of follow-up support for the loved ones in Paper V describes how the need for social support, both practical and emotional, after death is met mainly by their social network. Most of the respondents wanted and also received support from people in their social network. This is consistent with findings that the family contributes most of the social support for the bereaved (59,60). Even though families nowadays exist in many different forms, they still seem to find a space in which to give the needed social support in the different ways (42,61,84). On the other hand everyone in the network grieves at the same time which can reduce the possibility to give each other support. Professional support seems to be needed for the grieving person or for others in the network when they no longer cope with grief on their own and, had no one else to turn to, if they did not want to burden friends and family members. Bereavement research has recently pointed out that professional support is most needed when the grief becomes a complicated (49,52,53,92). It is difficult to distinguish between practical support and psychological/social support for the participants because the respondents did not differentiate support as dialogue versus practical help, but rather saw the support as a combination of the two. But they felt that all support was important. This can increase the value of support in many dimensions, practical, emotional, through networks and in other specific ways as both Stylianos et al and Hedin have showed earlier (60,82).

When the SOC scales (44) were analyzed together with the other data there was no correlation between the variables of the relationship, age, gender and what the networks were like. Those variables could not provide information about which person who might need more support. In palliative care providing support to bereaved loved ones, both during the patient's illness and after the death, is an important task according to WHO:s declaration (11). The loved ones may need different forms of support from professionals in health-care to be as prepared as possible for the patient's death. Which form of support can depend on how the loved one can cope with the situation, on which phase of life the patient and the loved ones are in and what the network looks like. Follow-up activities after the patient has died need to be developed in order to find those loved ones who need support from health-care professionals during the bereavement after the patient's death.

METHODOLOGICAL CONSIDERATIONS

The aim of the thesis was to examine loved ones involved in palliative care. Focusing on the loved ones meant to choose those who are close and mean a lot for the patient. Even if they not are the main person, they are important to the patient and according to the palliative philosophy, the loved ones should be supported during the patient's disease as well as after the patient's death. In the first study the aim was to examine the social support in a bereavement process after death, making it necessary to do the research after the patient had died. The research carried out one year after the patient's death which seems to be a reasonable time as the loved ones have had the chance to reflect on how the period influenced their life but are still close enough to the time of death to be able to recall it. An exception was made for Study 1 b, which examined what the loved ones thought the social support would be so that later they could compare with what support they actually received. Therefore 2 month after the patient's death was chosen as the time when most of the practical things concerning the funeral had been dealt with but it still near the death and the social support has not yet crystallized. In the second study the aim was to examine the loved ones' experiences of being close to a dying person when the patient is being treated. This can be done either when the patient is still being treated or after the patient has died. The same time as in the Study 1 was chosen in order to have the same circumstances in the research project as possible.

It is not possible to examine how the loved ones feel and how they can cope with such a situation without talking and reflecting on from the participant's experiences. The goal of the in- depth interviews is to encourage the interviewee to reflect on the phenomena of interest for the research (103). Even if qualitative methods use smaller samples for data collection, this is a way of collecting data which cannot be written down and described on a questionnaire by the participants. The interviews however are written down, word for word. In order to give the research trustworthiness the data collected and the invited participants have to be relevant regarding the aim of the study, represent a similar context and similar circumstances; the data collection has to be comprehensive and content analysis has to be applied to the material(96, 97).

A multi and mixed method was chosen in Study 1 to investigate social support. Methods were mixed in order to meet the ambition both describe the forms of support provided and to investigate on a deeper level whether the needs for social support was met and how such

support could be optimized and experienced during the first year of bereavement. The methods used were both questionnaires and in-depth interviews. The mixed methods allowed comparisons between the answers from the questionnaires and the content of the interviews. As no existing questionnaire was found about who provided social support, one was developed in cooperation with a professor in Social Work at Gothenburg University, Department of Social Work which met the research aim by providing open-ended questions. Social support was divided into psychological/social support and practical support. The reason for this was to examine whether the social support was connected more to emotional support and differed from practical support, which could concern more practical matters and things that the provider helps the bereaved to do. The result shows some lesser differences with more help in practical matters coming from the family and some psychological/social help coming from friends. The SOC questionnaire is an evaluated questionnaire which estimates the Sense of Coherence and was chosen to examine whether there was some correlation between sense of coherence and which form social support was needed. No such correlation was found, which shows that other circumstances govern the need for support. The questionnaire about social support was used as an interview guide to ensure that the aim of the study was discussed. The results from the interviews and the questionnaire agreed.

In Study 2 the aim was to examine how feelings and ways of thinking were experienced in the situations of being a loved one of a dying person. This study had a qualitative design with in-depth interviews. In order to ensure that the aim of the study was discussed and the research aim met, an interview guide was developed and used. The results from the interviews show many similarities as all participants in the studies were chosen as being a loved one of a patient diagnosed with a cancer disease who had died one year earlier, in different clinics in the same hospital.

In both Studies 1 and 2 there were more women than men participants and more men declined to participate, especially those asked to participate in an interview. It has not been able to investigate why more men refused to participate, but those men who did participate did not differ from the females. The standpoint to exclude children under 18 years of age was decided because including children claims special skills. Nevertheless it would be of interest in another study to focus on the children's perspective on strategies and understanding. Using content analysis gives knowledge about what strategies the loved one use during the

patients' illness. The content analysis can focus on the experience and phenomena as well as to find similarities and differences being in a special phase or situation in life.

Study 3 had a quantitative design with the research aim of professional carers opinion about loved ones' understanding and need for support. As no existing questionnaire was found in the literature, the research group developed the questionnaire covering various aspects of the research aim. The questionnaire was piloted among different professions such as nurses, doctors and social workers, at the hospital and some modifications were made before it was handed out to the participants. A power analysis was done to ensure there was sufficient material for a statistical analysis and the number of answered questionnaires was sufficient to give reliability to the results. It was possible to find both differences and similarities among the various categories including profession, age, gender and clinics.

CONCLUSIONS

This thesis was conducted in order to increase knowledge and understanding about being a loved one of a dying patient as well as about the need for support during the illness and the bereavement period.

The major findings of the thesis were:

- Most of the loved ones knew all the time that the disease was going to end the patient's life in the near future. This information was conveyed in many ways, talking to the professional carers, through the progression of the disease itself as well as in the conversations between the loved ones and the patient.
- There are several ways of expressing this knowledge, both directly and through symbols, which allows difficult things to be expressed more easily.
- Information gives the loved ones a chance to be prepared for approaching death and for a life without the patient in the future.
- The loved ones use different forms of strategies in order to cope with daily life and keep life as ordinary as possible.
- The information and preparation influence the grieving process
- It is in conversations with the loved ones that the professional carers can estimate the loved ones' need for information and the way they use strategies. These conversations are important as they allow the professionals to discover the various forms of support the loved ones may need.
- Support after death is mainly given by the loved ones' own networks, but in special circumstances there is a need for the involvement of professional carers.

PRACTICAL IMPLICATIONS

The findings in this thesis can lead to a deeper understanding of being a loved one of a dying person. The research shows that it is important to increase knowledge about the various strategies the loved ones use, so that carers are able to estimate whether the loved ones are using a strategy or are in denial.

The thesis also shows that it is important for the professional carers to be aware of how the loved ones obtain information; that it is not only conversations but also more implicitly through interpreting the symptoms of the disease and the use of symbols instead of clear words.

Information is an important task both for understanding what is happening during the progress of the disease and for the loved ones' inner preparation for the approaching death. These are two crucial factors which also influence the bereavement process for the loved ones after the patient's death. Thus educating the professional staff and developing methods that will help them to have such conversation, is one way of raising the quality of the care. Such measure would probably increase the knowledge of the professional staff with reference to discussing difficult subjects with the loved ones regardless of whether the patient is in a special palliative care or receiving some other form of care in a palliative phase.

WHO estimate that support for the loved ones both during the patient's illness time and in the bereavement process is a task for those who provide palliative treatment. The bereavement process whether it is an anticipatory grief during the patient's illness or after death, is filled with emotions and sadness. Routine follow-up of loved ones after the death of a patient seems to be one way to identify early on those who need extra support in the grieving process.

Professional support timely offered, may help to counteract grief stagnation, and thereby avoid the risk of future psychological dysfunction.

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Appendix 1 :

The interview guide for Study 2

What is your relationship to the person who was sick and later died?

How long was the illness?

How and when did you get information about the consequences of the disease?

When did you understand that the disease was incurable?

What was your experience of receiving this information?

When did you understand that the patient was going to die?

When did you understand that death was near?

What is your opinion about the information you received today?

How did the disease influence your remaining time together with the patient after you had been informed of the consequences of the disease?

Did you talk about the approaching death with others?

How did you manage daily life during the patients disease?

How was your experience of having thea possibility to prepare for the death?

What is your experience of this time, when you think about it today?

Is there anything more you want to tell which you think is important?