This thesis is a mother’s story about support in palliative home care, grief and bereavement.

The communication between her adult dying son and herself, between a palliative home care team and family caregivers and in the support during the first three years of grief and bereavement is described and analyzed. Trust, flexibility, continuity, accessibility and empowerment were key concepts in the communication between the family caregivers and the palliative home care team. Empathy based on institutions, on compassion, on shared experiences and loss—but also empathy to self—contributed to the mother’s reconciliation.
COMMUNICATION IN PALLIATIVE HOME CARE, GRIEF AND BEREAVEMENT
LENA HOLMBERG

COMMUNICATION IN PALLIATIVE HOME CARE, GRIEF AND BEREAVEMENT

A mother’s experiences

Malmö högskola, 2007
The Faculty of Health and Society
To all I love and to all who care for them
ABSTRACT

In this study a mother’s experiences of communication between her adult son dying in leiomyosarcoma and herself (the author), between his family and a palliative home care team and communication in the support of the mother in her parental grief and bereavement are described and analyzed.

The mother’s experiences are captured in personal accounts, writings, during the year of her son’s illness with cancer and his palliative home care and during three years of grief and bereavement after her loss. The data analysis is carried out in four steps by the mother as a researcher:

1) Identification of events of experiences of communication and significant concepts in the writings

2) Construction of four narratives, illustrating the concepts and including excerpts from the writings

3) Interpretation, contextualization and validation of the narratives

4) Contextualization in broader contexts.

The son’s hope and disavowal and the mother’s fear and despair emerged as important concepts in understanding the communication between them during his palliative home care. Recognition, acknowledgment and respect from the palliative home care team supported the mother.

A network of supportive arrangements was made available to the son and his family. The team recognized the son’s and the family members’ emotional needs as well as the family members’ needs to do anything they could for their husband, father, brother and son. Trust was a key concept in the communication between the son and his family on one hand and the palliative home care
team on the other. Trust seems to be a base for the empowerment of the family members. Main factors besides the team’s medical professionalism influencing trust were flexibility, accessibility and continuity.

Information, control, friendship and shared experiences were important factors in supporting the mother in her first year of bereavement. The findings point to the necessity of customizing bereavement support, specifically for high risk mourners.

In the short term perspective the mother found support in her pre school aged granddaughter, who had lost her father. These contacts provided breaks in the grief, actualized positive memories, established and sustained rituals. In the long term perspective confirmed family bonds helped the mother in her reconciliation process.

Empathy, based on the welfare system, providing flexible structures in which the mother was recognized and acknowledged, felt trust, was looked upon as an individual, was empowered and finally was reached by support after her loss, was of substantial importance to her. Empathy based on compassion, shared experiences, shared loss and strengthened family bonds supported her. Empathy to self allowed her to make use of the support she received and was part of her reconciliation process.

Keywords: Bereavement, communication, family caregiver, intergenerational relation, palliative home care, parental grief, reconciliation, support.
CONTENTS

INTRODUCTION ........................................................................ 11
BACKGROUND ........................................................................ 14
   Lay caregivers in palliative home care .................................................... 14
   Communication about and in end-of-life care, grief and bereavement ......... 16
   Grief and bereavement ........................................................................ 17
   Parental grief ....................................................................................... 18
   Research methods in palliative care, grief and bereavement .................... 19
OBJECTIVES ........................................................................ 28
APPROACH ........................................................................ 29
   Summing up ........................................................................................ 37
CONCEPTUAL FRAMEWORK ...................................................... 38
METHOD ................................................................................ 42
   Data collection .................................................................................... 42
   Data analysis ..................................................................................... 46
   Ethical considerations ......................................................................... 52
   Summing up ........................................................................................ 52
HOPE AND DISAVOWAL VERSUS FEAR AND DESPAIR .............. 58
   Introduction ...................................................................................... 58
   A narrative on communication. A dying son and his mother .................... 60
   Interpretation ..................................................................................... 66
COMMUNICATION IN ACTION BETWEEN FAMILY CAREGIVERS
   AND A PALLIATIVE HOME CARE TEAM ....................................... 78
   Introduction ...................................................................................... 78
   A narrative on communication in action ................................................ 79
   Interpretation ..................................................................................... 85
WORDS THAT MADE A DIFFERENCE IN GRIEF AND BEREAVEMENT ... 92
   Introduction ...................................................................................... 92
   A narrative on words that made a difference in grief and bereavement ...... 92
   Interpretation ..................................................................................... 97
INTRODUCTION

This thesis is based on experiences I wish I did not have and others that are precious to me. It is about experiences of communication in relation to life and death, devastation and empowerment, tears and smiles, despair and hope, disavowal and honesty, between young and old. It is about words and actions that made a positive difference to me as a home palliative lay caregiver to my dying son and as a parent in grief after his death. Now that I have had the experiences, I will try to understand them and make use of them by sharing them. The process of making them understandable to myself and to others might be called a research process. This study is a way of sharing these experiences with an academic public. First person experiences are not usual in research on home palliative caregiving, grief and bereavement, and can be seen as a valuable complement.

Some years ago my son died in leiomyosarcoma after about a year of illness. A palliative home care team together with his wife, me and his mother-in-law cared for him during his last weeks. My experiences of communication, as captured in a diary and impressionistic writings, between my son and me during his trajectory to death, between the palliative home care team and our family, in the support I had during my first year of grief, and support from my preschool aged granddaughter are described and analyzed in this study. The writings are discussed in the chapter on methods. In the analysis of the writings I focus on words and actions that had a positive impact, i.e. the experiences of communication that were of positive significance to me. To concentrate on positive support is not unusual in studies on home palliative care and bereavement (Miettinen, Alaviuhkola & Pietila, 2001; Muller & Thompson, 2003). Experiences of the burdens and challenges are more often discussed in the research literature, an issue I will come back to.
Not before one year after my son’s death did I read the diary I had kept during his trajectory to death. The day after his death I had stashed it away, but I continued to write impressionistically about my son’s illness, care and death and about my own experiences of grief and bereavement. After a year I was ready to read, interpret and analyze my diary, with a focus on the experiences of the communication between me and my dying son, and our family and the palliative home care team. I wrote two articles on these experiences (Holmberg, 2006a, 2006b). After yet another year I read the impressionistic writings I had written on a less regular basis during my first year of parental grief. In the writings among other contents, experiences of the communication in the support I received were captured. A third article was written on support given to me during my first year of parental grief (Holmberg, 2007a). About three years after my son’s death experiences of communication between my son’s daughter and me during three years of grief were analyzed. The method for analysis is described in a forthcoming chapter on methods.

I have chosen to write this thesis in the third person or a passive voice tense, even if the use of passive voice and the avoidance of employing the first person “are hallmarks of positivistic texts” (Tierney, 2002, p. 385). I use this way of writing more to indicate a distance in time as well as in state of mind from the time when I had the experiences to when I analyzed them, even if the study is based on autobiographic data. The four narratives that are constructed from my writings are however written in the first person tense as they are constructed from my diary and impressionistic writings.

The choice to focus on positive experiences might emanate from my background as an educationalist. During years of teaching I have found it more beneficial to give positive examples than negative if there is a positive change to be achieved. An other reason is that during the most devastating time that had ever happened to me, my son’s illness and his death, I had a profound need of support—and was given it from a wide variety of sources. The support was not always delivered by professionals, whose value cannot be overestimated, but also by family and friends, and in different contexts. Perhaps the findings will encourage others to give support to those in need, and point to the fact that most of us sometimes can make a positive difference to each other.

What gives a researcher the right to tell another’s story as a method of representation? is a question raised by postcolonial and feminist critiques of ethnography (Cary, 1999). This is not an issue in this study. No one else could tell my story. The interpretation of the story, however, ought to be discussed. By
writing this thesis I invite the readers to take part of my story on palliative care, grief and bereavement and my interpretation of it and also to make their own interpretations.
BACKGROUND

To locate the study a frame of research on lay caregivers in palliative care, communication in palliative care and parental grief will be presented. The difficulties of doing research on dying patients, their family caregivers and bereaved parents are also discussed as an introduction to the section on the chosen approach.

Lay caregivers in palliative home care

Terminal cancer and other severe diseases do not only affect the patient but also the whole family. Terminally ill patients often; 80 percent in Sweden (Strang, 2005/2006), choose to spend as much of their time as possible at home, thus involving family members in the care process (Hudson, Aranda & McMurray, 2002). In Sweden about 95 000 persons die every year. About a third of them have a peaceful death, a third of them need some kind of palliative care, and the remaining third need advanced palliative care (Strang, 2005/2006). Not all of the patients in the last group receive the care they need. Both patients and family caregivers are more satisfied with care in palliative home care, compared with conventional and hospital care (Wennman-Larsen & Tishelman, 2002). Furthermore, family caregivers assume that their opinions about palliative care at home are shared by those cared for (Wilde Larsson et al., 2004) and in general believe that it was beneficial for their dying relatives to be at home (Wennman-Larsen & Tishelman, 2002). Probably the latter is true to an even greater extent, when the patient is young and has small children. It is not unreasonable to imagine, that young parents want to spend as much time as possible together with their families when time is limited.

It is important that the prospective home lay caregivers, family members or friends, have a say in the decision to care for a relative or a friend at home (Stajduhar & Davies, 2005), and that they are well informed about the
demands and challenges they are going to meet. The task must be embraced wholeheartedly (Wallskär, 2004).

In most studies on palliative home care, lay caregivers are either husbands or wives, and the patients are often older than 50 (e.g. Borneman et al., 2002; Brazil et al., 2005a, 2005b; Brazil, Bedard & Willison, 2002; Burns et al., 2004; Kirk, Kirk & Kristjanson, 2004; Mystakidou et al., 2005; Wennman-Larsen & Tishelman, 2002). For natural reasons cases of younger adult patients cared for by their parents are more seldomly reported.

Once the decision for home care has been made, the support given to caregivers, formal as well as informal, is of greatest importance for the care (Brazil et al., 2005a; Brobäck & Berterö, 2003; Koop & Strang, 2003; Stadjuhar & Davies, 2005). The research literature on palliative home care focuses to a large extent on negative aspects, e.g. physical, emotional, financial and social impacts of caring for a dying patient (Hudson, Aranda & McMurray, 2002; Lim & Zebrack, 2004), even if there are also studies on positive experiences (Howell & Brazil, 2005). The quality of end-of-life care is sometimes unsatisfactory for both patients and families. Without support, caregivers experience stress, burnout and bad health, which make them less capable of providing appropriate care to those in need (Green, 2006; Pitceathly & Maguire, 2003; Proot et al., 2003; Singer & Bowman, 2002; Stadjuhar & Davies, 2003).

Families need information about the availability of community services to support the patient emotionally and physically (Burns et al., 2004). Emotional support is specific and dependent on the process of social interaction. What happens when emotional care and support are delivered in different care settings and what strategies are used in managing emotional care and support need to be explored (Skilbeck & Payne, 2003). Only when researchers are allowed to document what happens can we know (Walter, 1997).

Lay caregivers frequently report unmet needs related to guidance and support (Hudson, Aranda & McMurray, 2002; Proot et al., 2003). However, there is a problem in defining need. Some attempts have been made, for instance to define need as “the perception of a discrepancy between resources available and those required” (Burns et al., 2004, p. 501). As a baseline prevalence of supportive care service provision such a definition is problematic. One might ask if it is at all possible to define need of support to caregivers in a general way that is unambiguous enough to be used as guidelines in specific cases.
Communication about and in end-of-life care, grief and bereavement

Honest communication and support in making decisions are areas of significant importance to dying patients as well as to their family members (Howell & Brazil, 2005). Research on communication in palliative home care often concerns communication about death, ways of delivering bad news, or the benefits of telling the truth even if it hurts (Fallowfield, Jenkins & Beveridge, 2002).

Kirk, Kirk and Kristjanson (2004) list six critical attributes of good communication: (1) playing it straight, (2) staying the course, (3) giving time, (4) showing you care, (5) making it clear and (6) pacing information. Communication in palliative care in general and in palliative home care specifically is often described as problematic (DelVecchio et al., 2004; Hudson, Aranda & McMurray, 2002; Ingelton et al., 2004; Sanders, 1992; Sawyers, 2002; Singer & Bowman, 2002), i.e. the attributes of good communication do not always characterize the communication. Even if physicians seem to favour open communication there are indications of a gap between theory and practice (Salander & Spetz, 2002). Reviews reveal that the process of nurse–patient communication fails to “acknowledge that communication is fundamentally about interaction between two or more people that develops over time and is highly dependent” (Skilbeck & Payne, 2003, p. 524). Moreover, there is little recognition that patients and nurses contribute collaboratively to the process of interaction, and that patterns of interaction vary in relation to the health care settings (Skilbeck & Payne, 2003).

Another way of describing problems in communication is given below as an introduction to a forthcoming discussion of narratives.

One day I returned to my room and found a new sign below my name on the door. It said ‘Lymphoma’, a form of cancer I was suspected of having. No one had told me this diagnosis. Finding it written there was like a joke about a guy who learns he has been fired when he finds some else’s name on his door. (Koch, 1998, p. 1185.)

Mostly, the communication described in research on palliative care is verbal. However, emotional support can be communicated in a variety of ways during comforting interactions, both verbally (affirming statements, reassurance, empathy, encouragement, sympathy and commiseration) and non-verbally (touch, increasing proximity) (Skilbeck & Payne, 2003). What is found in research on the relation between the nurses in palliative home care and the
patients might to some extent be applied also to the relation between family caregivers and the professionals. Also actions of a concrete characteristic can communicate emotional support. Examples will be given in the forthcoming narratives. It must however, be noted, that the biomedical interventions to the son from the specialized palliative home care team are not discussed in this study.

The suffering experienced by family members of dying patients is one of the most demanding and challenging tasks experienced by nurses (Benzein, Johansson & Saveman, 2004). In the 1960s Dame Cecely Saunders launched the idea that part-time professionals should care for the dying. In this way the professionals could still maintain their own private lives “without getting too attached to their patients or too burned out on their work” (Sanders, 2001, p. 51). Systematic assessment and interventions with families tend to be overlooked by RNs (Registered Nurses) if family members are not seen as important in the care and are not invited to participate. Inviting interactions on the other hand are considered when the family members are seen as important participants in the care (Söderström, Benzein & Saveman, 2003). Patients benefit from specialist nurses in palliative home care who focus on the delivery of emotional care and support to patients and their families by inviting family caregivers to participate in the care (Skilbeck & Payne, 2003).

**Grief and bereavement**

Grief and bereavement is personal and idiosyncratic (Brady, 2005; Dunne, 2004; Jordan & Neimeyer, 2003; McLaren, 1998), and the grief processes is unique to each individual (Clements et al., 2004; Cutcliffe, 1998, 2002). Traditional models of grief present structures for the grief process, illustrated in a stepwise progression out of the grief (Clements et al., 2004; Dunne, 2004; Sanders, 1992). These linear models often lack empirical support (Attig, 1996; Cutcliffe, 2004). However, there seems to be consensus about the healing power of time (Jordan & Neimeyer, 2003; Ringdal et al., 2004), though the reductions in distress can be very slow (Murphy, 2000). Traditional models of grief also emphasize bereaved people letting go of their emotional relationships with those who have died (Davies, 2004). In contrast, new perspectives focus on the social world and place emphasis on how connected people are to each other. Concepts of continuing bonds with the deceased, or of holding on to one's relationships with the diseased are integral to these new models (Davies, 2004; Moules et al., 2004), and parental preoccupation with the lost child is said to be supportive rather than destructive (e.g. Malkinson & Bar-Tur, 2000;
Sanders, 1992; Stroebe, 1992–1993). In contemporary research on grief and bereavement the question is not about whether or not to continue the bonds to the deceased, but rather how to hold on to the relationship.

The grief work hypothesis, described as a cognitive process of confronting a loss, of going over the events before and at the time of death, of focusing on memories and working towards detachment from the deceased, has been put under question. According to the hypothesis, suppression is a pathological phenomenon. Stroebe asks (1992–1993, p. 20):

> Is it really necessary to work through grief in order to adapt to a loss? Could suppression not lead to recovery? Are there occasions when, or persons for whom, grief work is not adaptive? And where does one draw the line between healthy grief work and unhealthy rumination?

Stroebe suggests a narrow definition of grief work as (1992–1993, p. 33):

> ... a cognitive process involving confrontation with and restructuring of thoughts about the deceased, the loss experience, and the changed world within the bereaved must live.

Contemporary models describe grief as a process and not as an endpoint (Clements et al., 2004) and as non-linear and individual. Bereavement is described as a chaotic and mosaic-like process (Cutcliffe, 2004). Hence, the lack of consensus on what is the optimal care for bereaved persons (Forte et al., 2004) is understandable. Accordingly, research should acknowledge the special and unique features of parental grief.

**Parental grief**

Child death is a relatively rare occurrence in our society and we do not normally expect that it will ever happen to us (Sanders, 1992). Parental grief is recognized as “the most intense and overwhelming of all griefs” as “it impacts not only upon the individual parent but the parent dyad, family system and society itself” (Davies, 2004, p. 506). “The death of a child is for ever” (Rubin, 1993, p. 285) and parental grief is said to be a lifelong task. The intensity of grief after the loss of a child most likely decreases over the time (Chentsova-Dutton et al., 2002) but it remains a source of pain for the rest of the life for most parents (Dean et al., 2005). Regardless of the age of the child the death of a child violates the law of nature and reverses the sequence of life events for the
parent (Handsley, 2001; Singg, 2003; Small, 1998; Wheeler, 2001). Reactions to losing a child are as varied as the number of parents and “unique features of types of loss deserve singular attention” (Rubin, 1993, p. 289). Rubin found that parents who lost an adult son at war still showed powerful responses, sadness and yearning to the loss after 13 years (Rubin, 1993). Sometimes reactions seem to occur in three phases: the avoidance phase, the confrontational phase, and the reestablishment phase (Singg, 2003). Other researchers have suggested that the reactions should be divided into five (Sanders, 1992) or six (Doka, 2005–2006) phases.

Research indicates that a mother who has lost a child belongs to a high risk group of mourners (Jordan & Neimeyer, 2003). Following the death of their children mothers are likely to suffer more from deterioration in physical health, report higher depressions scores, and to be more affected by the loss of their children than bereaved fathers (Znoj & Keller, 2002). There are indications that the older the child the harder the loss (Dean et al., 2005), the greater the parent’s anxiety and the deeper their depression (Davies, 2004; Kreichbergs et al., 2004). The reasons being that successful accommodation of the loss is compromised, the parents are excluded from the concerns of others, bereavement can be overloaded from other losses and health problems, the parents have less control and involvement in their adult children’s lives and their grief might be complicated with additional losses, such as losing contact with grandchildren (Singg, 2003).

**Research methods in palliative care, grief and bereavement**

Two data collection methods are commonly used in research on palliative care, grief and bereavement; large-scale studies and in-depth interviews (Stroebe, Stroebe & Schut, 2003), using quantitative and qualitative data respectively. Yet a third is random sample studies, in which the effects of interventions of different kinds are studied in relation to background variables.

One of the main advantages of large scale surveys is said to be that they use large representative samples allowing generalisations. As such they have an importance on a national and international level, where databases on illnesses, age at death, geographic areas, hospitals, length of care etc. can give overviews. These overall pictures are of course necessary for planning welfare systems.

Missing data is a problem in studies on palliative care, grief and bereavement. Some examples will be given; 47 percent of the 180 patients in the sample in a
study on validation and utility of Greek McGill Pain Questionnaire in cancer patients were omitted due to “difficulties in reaching them” (Mystiakidou et al., 2002a, p. 381), only 26 percent of the 239 patients in palliative care used the instruments on pain that were assessed in a study on self-reported pain, crucial to pain management (Shannon, Ryan & D’Agostino, 1995), 69 percent missing data in a study of distress in bereavement (Addington-Hall, 2000), 71 percent missing data in a study of cognitive variables in psychosocial functioning after the death of a first degree relative (Boelen, van den Bout & van den Hout, 2003b), 47 percent of the contacted parents in a study on bereaved parents’ experience of research participation did not want to participate (Dyre-grov, 2004), 88 percent of the bereaved parents who were invited to discuss prevention campaigns regarding fatally injured children did not answer the invitation (Girasek, 2003), only 37 percent in a study of bereaved carer satisfaction with the end-of-life care returned a completed questionnaire (Ingelton et al., 2004), 56 percent in a study on grief reactions dropped out (Chentsova-Dutton et al., 2002). The list could be made longer. Therefore, research results in studies referred to in this thesis are most often to be considered as indications.

The reasons for the large number of missing data are obvious. Patients in palliative care sometimes die during the data collection and others become too ill to answer questionnaires (Ringdahl et al., 2004). Another obstacle is that the time from being diagnosed as needing palliative care till death is often short, and many high risk mourners probably go undetected (Piper, Ogrodniczuk & Weideman, 2005). In a study by Higginson and Donaldson (2002) on care outcome in palliative patients the missing data of 19 percent was due to refusal to take part in the study (12 patients), the patients fell to unwell (11 patients) and died (8 patients). This is an indication that the missing data is not random, that in turn makes the findings not generalizable to the respective population of patients in palliative care. Another example of selective missing data is found in Cameron’s et al. (2002) study on emotional distress in family caregivers. The response rate was 46 percent and there is reason to believe that the refusers were caregivers under more stress than those who participated. The missing data is not always analyzed.

The reasons for the high frequency of drop outs in studies on parental grief are discussed in a study of prevention work. Only 12 percent of 68 families, whose children died in unintentional injuries and who were invited to participate, answered the recruitment letter. The reasons for not participating were analyzed. Acute bereavement, pain re-experience, issues of privacy, desire to main-
tain composure, denial, intimidation, competing commitments, unresolved litigation, fear of reproach, conflicting approach to prevention, unaware of avenues, discouragement, negative attitudes towards the media, objections of family members, and a desire to protect child’s reputation were mentioned. Reasons for participating were to save other parents from bereavement, to save children’s lives, to promote healing, to give meaning to their tragedy, to honour their child, because they are uniquely qualified, to right a wrong, to increase awareness of their plight, to increase impact of campaigns, and to meet other bereaved parents. (Girasek, 2003.)

Related to the missing data problems there is an ethical issue in researching dying patients and their relatives. Dying patients and their relatives are extremely vulnerable (Sanders, 2001). The ethical problem of asking dying patients to fill in questionnaires is profound. Not giving the dying patients a say is also an ethical dilemma. In some cases the patients give consent to be included in studies before they get too ill (Riley & Ross, 2005). In yet other studies the participation in clinical trials is said to foster the patient’s hope that future palliative patients can receive better treatment (Janssens & Gordijn, 2000).

One way of dealing with the missing data problem is to estimate missing data for a specific item from answers given on others, taken certain background variables into account (Powis et al., 2004). Another method is to have relatives, friends or caregivers give information on behalf of the patients. “The family perspective is of importance since proxy evaluations of the quality of dying are now common associated with obtaining the dying person’s perspective of the quality of EOL /End-Of-Life/ care received” (Howell & Brazil, 2005, pp. 19–20). In Paci’s et al. study (2001) 16 percent of the palliative patients did not themselves respond to an instrument measuring quality of life. Also the short survivors were dropped from the study. Hence, the problems of doing research on representative samples of patients in palliative care are manifold, due to problems relating to recruitment, attrition, and the vulnerability of the patient group, all contributing to making randomised controlled trials difficult (Grande et al., 1999; Grande & Todd, 2000). Making generalized inferences from research in palliative care is consequently often hazardous.

In large scale quantitative studies data is sometimes collected that is said to allow for “a fine-grained measurement” (Stroebe et al., 1992, p. 238) in different groups of i.e. bereaved persons. Sometimes questionnaires such as rating scales are supposed to be less researcher biased than e.g. interviews. This
claim can be put under question, as the researcher constructs the questionnaires from a specific theoretical standpoint, choosing from a wide range of possible questions, formats, scales etc. Questionnaires are not researcher independent, they are constructions. Furthermore, questionnaires are often complex (Riley & Ross, 2005), and

... measuring acceptance [of dying] by quantitative ratings alone could seem as incomplete as estimating illumination in candlepower. (Hinton, 1999, p. 33.)

Important dimensions may be missed simply because the researcher did not include certain topics in the questionnaire (Stroebe, Stroebe & Schut, 2003). An example is death anxiety scales that “inadequately represent the complexity of death-related attitudes of which death anxiety is only one dimension” (Wass, 2004, p. 300). However, there is also some evidence that a few screening items may be used to identify most psychiatric out patients with complicated grief, and thus be more productive than requesting clinicians to conduct thorough assessment for complicated grief (Piper, Ogrodniczuk & Weideman, 2005). On the other hand, to separate normal grief from complicated grief calls for a definition of normal grief in a manner that turns individual experiences into sociology (Craib, 2003) and contradicts the assumption that grief is individual. There is a risk that the lived experiences are reduced to platitudes in empirical research rooted in a positivistic tradition, and a phenomenological approach is suggested to overcome “the tendency of dealing with lived experiences in a banal way” (Öhlen, 2003, p. 557).

“There is little known about family members’ experiences and perceptions of quality of life when a family member is dying from the time of awareness of incurable illness to death” (Miettinen, Alaviuhkola & Pietila, 2001, p. 263).

Looking at carers’ experiences more widely, it would be particularly useful to examine them longitudinally, tracing changes in their feelings about their role, their interaction with professionals, and the coping strategies they adopt. (King, Bell & Thomas, 2004, p. 83.)

Research on qualitative data in the context of palliative care, grief and bereavement requires that the researcher intimately approaches “the pain in the family” and how the death is perceived by both patients and family members (Silverman, 2000). There are reasons to believe that studies concerning the relationships between nurses and doctors on one hand and family members in
palliative home care on the other are sparse. More research, including direct observations of interactions between nurses, doctors, and family members is paramount (Söderström, Bensein & Saveman, 2003). Utilising stakeholders to identify the consequences of interventions made by members of a palliative team is one way to ensure that cancer patients receive optimal palliative care (Jack, Oldham & Williams, 2002) and that family members taking part in the care are supported.

Listening effectively to patients and carers may lead to quite different and innovative lines of research and provide insights, which redirect research, and develop new, more appropriate methodologies and measurement tools. (Bradburn & Maher, 2005, p. 92.)

Practical, emotional and conceptual barriers could act as a spur to imaginative thinking rather than an excuse for inaction. Walshe et al. (2004) suggest a case study strategy in studies of complex situations, when context is central to the study, when multiple perspectives need to be recognized, when the study design needs to be flexible, when the research ought to be directly congruent with a clinical practice approach, when there is no strong theory to which to appeal, and finally when other research methodologies could be difficult to conduct. In the present study all the whens seem to be more or less at hand.

Research that studies the impact of palliative care on the patients’ experiences is required to ensure that cancer patients receive optimal palliative care (Jack et al., 2004). This is relevant regarding family caregivers of cancer patients as well. Through in-depth interviews variables of interest can be used in matching procedures, a longitudinal design is possible, and prospective as well as retrospective information can be collected (Stroebe, Stroebe & Schut, 2003). In-depth interviews also can provide information about background variables that often are not taken into account in large scale research on grief and bereavement (e.g. Mack, 2001; Neimeyer, Wittikowski & Moser, 2004). The same goes for research that focuses on dying persons.

When we talk about a person who is dying we need to know at least something about their history and character and we need to know something about the experience of dying. (Craib, 2003, p. 292.)

On the other hand “there is a tendency for sociologists to distort or suppress the complexity of experience precisely by trying to make sociological sense of it” (Craib, 2003, p. 287). Even so, it is very difficult to carry out randomized
controlled trials in palliative care for much the same reasons that cause missing data in surveys (Grande & Todd, 2000).

One method of data collection that has been used in studies of palliative care is the focus group interview (Howell & Brazil, 2005). When using focus groups in these studies the researcher does not have to confront the terminally ill, but can draw upon the informants’ e.g. nurses’ experiences. However, in such interviews there is a risk that the informants present generalized examples rather than specific, contextually situated examples. Another obstacle is the “extent to which group dynamics influence the data material”, e.g. by restricting informants from being open about problematic conflicts (Sandman & Nordmark, 2006). Furthermore, informants may risk breaching confidentiality in focus group interviews (Sandman & Nordmark, 2006). Research by nurses in clinical settings may “help bridge the gap between research and practice” (Tishelman et al., 2004, p. 421). The practitioner-as-researcher model is claimed to produce knowledge within a context to identify problems and take action to solve them (Bensimon et al., 2004). This idea could be extrapolated to advocating that lay palliative caregivers and the bereaved take an active part in research on lay palliative caregiving and bereavement as in this study.

Research using qualitative data on the experiences of family members caring for a dying family member has been limited (Miettinen, Alaviuhkola & Pietila, 2001; Perreault, Fothergill-Bourbonnais & Fiset, 2004) and is almost absent when the patient is an adult child (Dean et al., 2005). Nevertheless, qualitative research is said to have opened up for “most of the new vistas in bereavement and end-of-life research in this century” (Silverman, 2000, p. 472), but very seldom does research include family caregivers as partners in the palliative care (Burns et al., 2004). Palliative care certainly is an area, ripe for innovation and ought to be open to a wide range of research methods (Bradburn & Maher, 2005). Stories are one of the sources that might be used to further our understanding of terminally ill patients (Bradburn & Maher, 2005). This may also be relevant to those who care for a dying patient at home. Such an approach is valuable in research on intimate and painful experiences (Riches & Dawson, 1996).

In the present study on communication in palliative home care, grief and bereavement even the mother’s experiences of communication between herself and her pre school aged granddaughter is described and analyzed, as it had an impact on the mother’s grief process. Even if the granddaughter’s grief is not focused in the study some notes on the research on children’s grief will be
addressed, as theories on children’s grief have an impact on understanding the communication between the mother and her granddaughter. As few young children in Sweden lose their parents (SCB, 2003), data on small children’s grief is hard to collect. Moreover, the child’s language is still developing and to talk about grief is not only emotionally demanding but also needs a vocabulary. Few studies include children below the age of five (Brown, Pearlman & Goodman, 2004; Cooper, 1999; Curtis & Newman, 2001; Goodman et al., 2004; Schoen, Burgoyne & Schoen, 2004; Thompson & Payne, 2000). Furthermore, much knowledge about children’s grief is based on children with support from outside their families. Research on support services for bereaved children is often compromised by methodological weaknesses in the design of the studies, e.g. small sample sizes, irregular attendance, high levels of attrition, short time between pre- and post-testing and difficulty in developing appropriate instruments (Curtis & Newman, 2001). Rigorous methods using qualitative data are suggested to provide opportunities for theoretical and conceptual development, on which to build empirical studies (Dowdney, 2000). Another problem for researchers is that there is seldom an opportunity to be close to a grieving child over a period of many years. Thus the development of grief in children is most often studied in cohorts of children of different age groups. Consistency is reached on children’s grief according to their development (Cohen et al., 2004; Glazer & Marcum, 2003). Even so, children’s individual grief needs to be studied, and the need for longitudinal studies on children’s grief is evident (Stokes et al., 1999). A case study can be appropriate and valuable because it “embraces the dilemmas and provides for a reflexive approach” (Jones, 1997, p. 239) and makes it possible to follow a case for a longer time period.

There is a need to complement standardized measures with information that discloses a bereaved person’s perspectives in their own words (Holcomb, Neimeyer & Moore, 1993). In a review of the book “Crossing over: narratives of palliative care” by Barnard et al. (2000) the reviewer writes (Exley, 2002, p. 510):

Personally, I would have preferred to see the respondents’ own words appearing much more frequently throughout the book without the voice/opinion of the researcher appearing to dominate so much.

The caregiving families’ voices remain largely unexplored (de Graves & Aranda, 2005). Research is needed to sound lay as well as professional views of the role of palliative care services (Addington-Hall & Karlsen, 2005; Perreault &
Fothergill-Bourbonnaiés, 2004; Riley & Ross, 2005). It is important to involve family caregivers in research aiming at identifying the type of interventions, that are most supportive in home palliative care (Miettinen, Alaviuhkola & Pietila, 2001; Sherwood et al., 2004) and to use the “wisdom of hindsight” (Hudson, Aranda & McMurray, p. 264). There is also a need for research on caregiver self-efficacy in the period of bereavement and beyond (Kazanowski, 2005) as “the stories of the bereft are rarely heard” (Handsley, 2001, p. 10).

A call for “New approaches to assessing qualitative data, such as journal entries and other personal narratives” (Wass, 2004, p. 300) and methodological pluralism (Stroebe, Stroebe & Schut, 2003) has emerged. Primarily descriptive studies, that can illuminate the experiences of those receiving palliative care can lead to improvements in the care (Froggatt et al., 2003) and of bereaved persons “without the framework imposed by the researchers” (Muller & Thompson, 2003).

... evidence of hospice success has come largely from qualitative studies, clinical reports, and a wealth of personal narratives and testimonials by patients and their families. (Wass, 2004, p. 292.)

The present study contributes to the needed research on how palliative home caring interactions influence an individual family member (Söderström, Benzein & Saveman, 2003) from a caregiver’s point of view. In this study the son was in his late 30’s when he was diagnosed with cancer and the study therefore adds to the knowledge of parental loss of an adult child through the perspective of a parent’s experiences. The bereaved mother’s experiences of communication between herself and her pre school aged granddaughter is described and analyzed, contributing to a more complete picture than is given in the research literature of the relationships between grandparents and their grandchildren in the case of parental loss. A reconciliation process is described by first hand experiences so as to complement the knowledge achieved by research methods where other kinds of data are used. A study originating from personal experiences and analyzed by the person who made the experiences demands that the researcher’s interest is explicitly told. The interest in this study is translated into the objectives for the study. Input of perspectives and theories in the analysis of the constructed narratives emanates from literature and is chosen by the mother as a researcher and not by an outside researcher. This might be a limitation that will be further discussed in the following.
Above, some issues in the field of palliative care have been identified, pointing to some of the problems involved in researching this field. In the following four chapters the objectives, approach, conceptual framework and method of the study will be elaborated on.
OBJECTIVES

To lose a child from death and to grieve the loss are the most devastating experiences a parent can face. And yet many parents reconcile and go on living reasonably good lives. What supported a mother facing these experiences is the overall concern of this study.

There is a problem in research in palliative care to give voices to patients and those who live on after the patients’ death. They are most often the objects for research. In this study a voice is given to a mother’s experiences of communication during palliative home care for her dying adult son and in her grief and bereavement after the loss of her son to reveal what supported her.

The objectives for the study are:

- to describe what experiences of communication had a positive impact on a mother during lay caregiving in palliative home care of her adult son and in her grief and bereavement process, and
- to analyze why experiences of communication during lay caregiving, grief and bereavement had a positive impact on the mother.

The mother’s experiences of communication in four different settings are described and analyzed to reach the objectives, namely

- between her dying son and herself in relation to the intervention from a palliative home care team,
- between her lay caregiving family and a palliative home care team,
- in support given to her in her grief and bereavement during the year after the death of her adult son, and
- between herself and her fatherless granddaughter.
APPROACH

Sometimes in our lives we can be “both the subjects and the objects of the work in which we are involved” (Silverman, 2000, p. 469). The quotation is relevant for this study. It is carried out by a mother, who as a subject experienced communication as a lay caregiver to her dying son in his palliative home care and as a parent in grief and bereavement. The mother is also the researcher, who analyzes and interprets the experiences as objects. This approach needs to be elaborated on and discussed.

The study is based on the experiences of a single person, a mother, as described in personal accounts. From the personal accounts narratives are constructed. “The use of an autobiography of the researcher, rather than the biography of the researched has rarely been used explicitly, even when the research methodology is ethnographic” (Haynes, 2006, p. 404). The vexed question of the relationship between the researcher and the researched is an ongoing discussion in ethnographical research, a field into which the study can be placed, according to the broad use of the concept autoethnography advocated by Ellis and Bochner (2000, p. 739).

Three alternative visions for an approach where the researcher reveals herself is outlined by Atkinson, Coffey and Delamont (2003, pp. 68–69); consolidation, new ethnography and beyond ethnography? The first vision, consolidation, advocates that “personal self cannot, nor should not, be separated from the practical, intellectual, and social processes of qualitative research” and implies “recognition that the self is part of the field and part of the text”. In the new ethnography scenario the boundaries of qualitative research are said to be widened/blurred/disrupted. One feature in the new ethnography vision is that it “draws on the therapeutic and analytical value of personal narratives and self-stories, and makes visible that which is often dismissed or rendered invisible in qualitative inquiry”. Finally “it is debatable as to whether utilizing
ethnographical strategies to write autobiography really counts as ethnography at all”, i.e. that it is beyond ethnography.

The three visions for the future all have their advocates. In this study in which autobiographic data is used to analyze experiences of communication in different settings made by a mother who is also the researcher all three visions might be applied, depending on who is applying them. In the field of palliative care, grief and bereavement the first person’s voice is seldom heard, implying that even if a consolidation vision is embraced the approach is hardly used in the field. The mother as a researcher is well aware of the difficulties in analyzing her own autobiographic data and the challenge of moving back and forth in the field of personal accounts, theories, research, and memories. However, it is up to the readers to judge whether she succeeded to make this navigation a scientific piece of work. And—most likely—different readers will come to different conclusions. In the following some arguments in favour of the consolidation vision will be addressed.

The choice of using first or third person tense in this study is not facilitated by recommendations in the research literature in the palliative field. And yet, “the author’s voice is one of the more critical pieces of a narrative puzzle” (Tierney, 2002, p. 395). As the study aims at understand “some aspect of a life lived” and is personal the author should become “I” and the readers “you” (Ellis & Bochner, 2000, p. 742). Even so the analytical parts of the study are written in the third person or passive voice tense, even if the author is conscious about that it might reproduce “the static narrative forms found in traditional, scientist-oriented research” (Tierney, 2002, p. 385). The choice is made out of conventional reasons.

The individuals’ own interpretation of self is focused in narrative research. “We seem to have no other way of describing ‘lived time’ save in the form of a narrative” (Bruner, 1978, p. 12). Goodson refers to a representational crisis when he talks about the central dilemma of trying to capture the lived experience within a text. “At root this is a perilously difficult act” (Goodson, 1997, p. 112). On the other hand Atkinson, Coeffey and Delamont do not refer to a “crisis of representation” when talking about researchers’ choice of styles and formats. “If it is a crisis, then it is a very protracted spasm” (2003, p. 190). Rather they point to the fact that scientists since long have used a variety of different representational styles.
The “Life historians believe that the stories people tell about their lives can give
important insights and provide vital entry points into the ‘big’ questions”
(Goodson & Sikes, 2001, p. 2), e.g. questions related to life and death. The
rationales behind using storying as a scientific method are summarized as
(Goodson & Sikes, 2001):

- It explicitly recognizes that lives are not hermetically compartmentalized
  and that anything that happens to us in one area of life potentially has
  impacts for other areas too.
- It acknowledges that there is a relationship between individuals’ lives on
  one hand, and historical and social contexts and events on the other.
- It provides to show how individuals negotiate their identities, experience,
  create and make sense of the rules and roles of the social worlds in which
  they live.

Knowledge about communication in palliative care, grief and bereavement
does not simply exists, rather it is produced and reproduced in response to
specific circumstances and discourses (Haynes, 2006). Therefore, “narratives
that make up people’s stories, … are linked to broader social narratives”
(Haynes, 2006, p. 402). The mother’s experiences of communication will be
linked to social narratives on what is talked about as a good death, and what it
is to grieve and to be bereft. These broad narratives develop over time and
cultures as they are also products of the actors who construct them (Seale,
2004). A starting point in this study is that we narrate our lives in the society
to which we belong. Thus the broad narratives in society have an impact on
our individual narratives.

In autobiographic research the writer’s place (the fusion of researcher and
researched) is often challenged (Koch, 1998). One might ask “how do we con-
vince others that telling stories is a legitimate research endeavour?” (Koch,
13).

... the story of one’s own life is, of course, a privileged but troubled narrative
in the sense that it is reflexive: the narrator and the central figure in the
narrative are the same. (Bruner, 1978, p. 13.)

Rather than seeing the obstacle in using our own subjectivity as researchers we
should scrutinize how we use our subjectivity as part of the research process.
“Feminist research views bias not as an influence that distorts the findings of a
study but as a resource and, according to feminists, sufficiently reflexive researchers can evoke the bias for understanding their interpretations and behaviour in their research” (Olesen in Dowling, 2006, p. 14). Reflexivity “closes the door on a belief that researcher objectivity and researcher-participant distance is paramount and opens a door to the transparency of reality” (Dowling, 2006, p. 18). It might even be transparent and methodologically valuable to include the researcher’s autobiographical material (Haynes, 2006). An autobiographic study is not mediated by a researcher who “has a vested interest in the story” (Dhunpath, 2000, p. 549).

In her introduction to an autobiographical essay on parental loss Cain points to the pragmatic use of bringing real life into teaching of carers for the bereaved (in Waisanen, 2004, p. 291):

There is much in this essay that will immediately resonate for students of bereaved and caretakers of bereaved.

The essay let the reader experience empathy, torture, fragility, deterioration and disfigurement in a way a rating scale or a questionnaire would never be able to. It is a challenging enterprise to identify and reflect on the contexts that affect an autobiographical text (Sharkey, 2004).

One might question whether a researcher is too close to be able to analyze her own experiences. Other researchers might have come to other conclusions than the autobiographer. The question is whose analysis are most credible. It is up to the researcher to draw on the advantages that closeness give and try to avoid pitfalls caused by the closeness. In a study on clinical practice and the human experience the researcher realized (Silverman, 2000, p. 476):

… how hard it is to be close to the pain of the children that we were studying until I had experienced a bit of it myself.

“The autobiographical life story can by definition only be told as lived experience, that is from the position of the experienced” (Steffen, 1997, p. 107). Individual experiences can be told either as life stories, that is to include a historic dimension, or as anecdotes, that is to be allegoric. Collective experiences on the other hand are told in case stories that have a history and in myths that are allegoric. (Steffen, 1997.)

Autobiographies present us with the small narratives that make up the overall understanding of living and dying with AIDS.

The problem of how to integrate our professional and private selves is described as the doubting game and the believing game, where the former challenges people by asking for proof, a role ascribed to the traditional researcher that values the outsider’s objectivity. The latter allows for participants to try to take each other’s point of view. Personal experiences and feelings are valued and respected as reference points and ways of learning and making meaning (Silverman, 2000). In this study the believing game is played when narratives are constructed and told and the doubting game is played when research in the field of palliative care and grief is related to the narratives. To use the wordings of Stadjuhar, Balneaves and Thorne the study is placed in a philosophical “middle ground” position (2001, p. 79).

It means setting aside the role of outsider by seeing the limitations of objectivity and recognizing that we are dealing with issues of our common humanity. (Silverman, 2000, p. 475.)

A more radical standpoint to empiricism stresses interaction and context as determining the production of knowledge and claims that we can only understand others from within our own knowledge (Steffen, 1997). The autobiographer’s experiences allow the data to be studied deeply and in perspective (Silverman, 2000). An expression of “A Third Culture” in research is coined. The first two being controlled conditions in a laboratory like setting and clinical situations. The third culture is “the culture of the human condition” (Silverman, 2000, p. 474). It can be revealed by an autobiographical approach, that by definition is built on lived experiences and told from the position of the person with the experiences. There seems to be no clear cut demarcation line between the cultures. In a study on deaths at home Raunkeær describes the dilemma of being the observer in dying patients’ homes. One of the patients was followed during 13 months due to his “wishes to have contacts with the
researcher” (Raunkiær, 2007, p. 61, the author’s translation) and not because the design of the data collection. The dilemma to separate the roles of a distanced researcher and an engaged human being thus might be a dilemma also in clinical research that does not use autobiographical data.

A literature search of studies in the field of palliative care, grief and bereavement with an autobiographical approach is summarized in table 1.

Table 1. Overview of the literature search regarding autobiography research in the palliative field

<table>
<thead>
<tr>
<th>Database</th>
<th>Words</th>
<th>Number of studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Academic Search Elite</td>
<td>Autobiography + palliative (1900–2006)</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Autobiography + grief (1900–2006)</td>
<td>9</td>
</tr>
<tr>
<td>PubMedCentral</td>
<td>Autobiography + palliative (1900–2006)</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Autobiography + grief (1900–2006)</td>
<td>7</td>
</tr>
<tr>
<td>CINAHL</td>
<td>Autobiography + palliative (1900–2006)</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>Autobiography + grief (1900–2006)</td>
<td>9</td>
</tr>
</tbody>
</table>

Few studies were found in which the researcher was also the autobiographer, and in which the palliative care or the parental grief concerned an adult child. The studies, in which the researcher is also the researched, includes a counsellors’ perspective of grief counselling (McLaren, 1998). Interestingly enough, the author identified his study as a case study and not a research-based paper. In a study on sibling grief narrative methods were used to retrospectively construct a personal story, that describes a researcher’s grief and loss experiences following her brother’s AIDS-related death (Eaves, McQuiston & Shandor, 2005). In a study on the residual effects of sudden death on self-identity and family relationships the researcher draws upon his own experiences with terminal illness. The researcher intended to supply a thick account of both the positive and the negative outcomes of “coping with the tragic and untimely loss of a son and a brother” (Handsley, 2001, p. 25). The aforementioned study of his own fear in facing death is yet another example of an autobiographic account (Craib, 2003). In Gili’s book her mother, also a researcher, tells about her 11-year-old daughter, who died in an accident, and analyzes grief and bereavement from a mother’s perspective. Although being a professional psychologist the mother writes that nothing in her professional or personal experience had prepared her for the devastation of her daughter’s death (Kagan (Klein), 1998). In an article on the essence of caring for a dying
person one of the authors tells about her mother’s living while dying, using narratives as starting points to conclude the importance of family support in caring for a loved dying family member (Johnson & Bourgeois, 2003). Even if not autobiographical, Sanders draws upon her own experiences on loss and bereavement. Her entry into thanatology was both circuitous and deeply personal (Doka, 2005–2006; Sanders, 1992, 2001). After the loss of her 17-year-old son she developed an instrument, the Greif Experiences Inventory, and formulated a stage theory on grief, including five universal phases: shock, awareness of loss, conservation and the need to withdraw, healing and renewal (Sanders, 1992).

Some studies are found in other fields. From a feminist theoretical perspective Haynes argues that “the use of autobiography is a methodological principle, which links epistemology and ontology with methodology” (Haynes, 2006, p. 400). Gould (1995) draws on the dual role of being a consumer and a researcher when studying consumer behaviour. In the field of education there are a number of self-studies, that are built on the researchers’ own experiences. These studies are often a result of confusing challenging experiences (Freese, 2006). Steedman (1985) used her own experiences as a starting point in understanding the primary school teacher in a historic perspective.

A common trait in autobiographical research articles is that they use impressionistic writings as data, often elaborated into narratives. In the above mentioned study on adult sibling grief one of the authors’ narrative was used as data. The definition of narrative used in the study was

... a meaning structure that organized events and human actions into a whole, thus attributing significance to individual actions and events based upon their impact on the person. (Eaves, McQuiston & Shandor, 2005, p. 141.)

In the chapter on method the definitions of narrative and story will be discussed.

Primarily there are two kinds of narrative research. In one, narratives are collected and analyzed in order to arrive at generalizations about a particular group, work or career story. Life history research on teachers is an example. In a second type materials from a particular subject, individual or system are collected to construct a narrative that renders meanings inherent in or generated by a particular object (Elbaz-Luwisch, 1997; Polkinghorne, 1995).
The boundaries between the two kinds of narrative research are not clear cut (Elbaz-Luwisch, 1997). In the present study narratives are not used to make generalizations, but to describe and analyze a mother’s experiences of communication in palliative home care, grief and bereavement, so as to reveal the meaning the experiences had to her. Thus, the results will not tell how communication in palliative home care and grief and bereavement impacts parents in general, but how it can have a positive significance according to a mother’s experiences.

The study can also be described as a case study, depending on how such a study is defined. McLaren categorizes, as mentioned, his article on his own work as a counsellor as a personal and impressionistic case study of one counsellor (1998). “The lack of an accepted definition has resulted in case study meaning different things in different research traditions” (Walshe et al., 2004, p. 677). Merriam (1988/1994) summarizes a case study as

... an intensive, holistic description and analysis of one entity or phenomenon. Case studies are particularistic, descriptive, heuristic and depend to a great extent on inductive reasoning ... (Merriam, 1988/1994, p. 29, the author’s translation.)

These characteristics are relevant for the present study. Furthermore a case study aims at an interpretation within a contextual framework (Addington-Hall & Karlsen, 2005; Merriam, 1994). “The use of a case study can clarify the setting and the concerns expressed by patients” (Green, 2006, p. 294). Case study strategies are appropriate to study complex multivariate conditions and not just isolated variables. As palliative care, grief and bereavement are complex, patient focused, context dependent and multiprofessional such a strategy might be useful (Walshe et al., 2004). In a case study the case must be defined. The case in this study is a mother’s positive experiences of communication during palliative home care of her dying son and during her first years of grief and bereavement, i.e. what the study aims at generating knowledge about (Patton, 1980). Three types of case studies can be identified; intrinsic, instrumental and collective case studies (Stake, 2005). An intrinsic case study is carried out purely to understand the particular case, whereas an instrumental case study of a particular case “mainly provide insight into an issue ...” and “the choice of case is made to advance understanding of that other interest” (Stake, 2005, p. 445). In a multiple case study several cases are studied to investigate a phenomenon, population or general condition. The present study can be categorized as an instrumental case study, as the case, the mother’s
experience of communication, is used to contribute to the understanding of what can make a positive difference to a mother in palliative home care and why the communication can be experienced as supportive. Theoretically another case might have been chosen, but it is questionable, according to difficulties in data collection in the field, whether data not being autobiographic, would have been as close and condensed, and given the same opportunities to learn (Stake, 2005). The main point is that it is not the particular mother, who is the ultimate interest for the study, but positive impacts of communication in palliative home care, grief and bereavement, i.e. “to learn from the case about some class of things” (Peshkin in Stake, 2005, p. 447).

**Summing up**

As a researcher the mother constructs four narratives about her experiences of communication during a very specific time of her life based in a diary and impressionistic writings. Thus, the data is autobiographic. This might be considered a major limitation but also a benefit as research in spite of its systematic demands also is “dependent upon coincidence, intuition and insight” (Riches & Dawson, 1996, p. 2). The autobiographic data also reflects the mother’s development during palliative home caregiving and as a bereaved parent, as they are written over a four year period.

Three articles based on the mother’s experiences of communication are written and published (Holmberg, 2006a, 2006b, 2007a); two focus on her experiences during her son’s palliative home care and one concerns her grief and bereavement. Another article is written but is as yet not accepted for publication (Holmberg, 2007b). The articles are not, in their entirety included in this study, the reason being that they are written on different occasions, starting from the first year of grief to the third year, and thus mirror different stages in the mother’s grief and reconciliation process. In this study the mother has reached a stage of reconciliation, where she can also view the articles in a time perspective and elaborate on the interpretations made in the articles and review them in retrospect. The narratives constructed in the articles are however also used, with some minor alterations, in this study.

A discussion about limitations and benefit of the approach is needed and will follow after the presentation of the findings.
CONCEPTUAL FRAMEWORK

In this chapter some of the vital concepts used in the study are presented and their use is described. Stipulative definitions (Pedhazur & Pedhazur, 1994) are also given.

*Experience of communication*

The definition of communication used in this study is wide. The Latin word communis can be understood as shared, and communication as the way to share information, ideas, feelings, and attitudes. Not only verbal communication is taken into consideration, but also communication shown in actions and mediated through things is analyzed. It is most important however that communication is not studied per se, it is the experiences of communication that made a positive difference to the mother that are focused.

*Palliative home care*

Palliative care is defined according to WHO (2006).

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.

This definition also includes the quality of life of the dying patient’s family. In an appendix (WHO, 2006) the process of grief and bereavement after the loss is included in the definition. In the guidelines from the EU Council on palliative care, also support to relatives after the patient’s death is mentioned (Council of Europe, 2003).
The palliative home care in the study was provided by an advanced home care team. Such a team is physician-led, multiprofessional, includes qualified medical technology services that are available 24 hours a day seven days a week, has a hospital bed standing by, has a large reception area, and is primarily concerned with palliative care (Stoltz, 2006). The word advanced is omitted in the study when the home palliative care team is referred to, even if the care for the son met all the criteria above. This kind of palliative care is also called specialized palliative care, being a higher standard palliative care provided at an expert level (Ahmedzai et al., 2004).

**Family caregiver**

In a study by Stoltz the family is defined as “who they say they are” (2006, p. 17). Such a definition is broad, and implies that family members self-define the family, and that the individuals might be connected by blood or legal ties (Kristjanson & Aoun, 2004; Stoltz, 2006). In the present study the definition can be more precise. The son, his wife and their three-year-old daughter formed the core family. The son’s mother, father, mother-in-law and his sister, brother and their families were all family members who were more or less involved in the son’s life during his illness. All together they constituted his family. His wife and mother were the primary home lay caregivers. His mother-in-law took on a substantial part of the care of his daughter and his father helped out with practical matters not immediately related to the care.

A family caregiver has been defined as “the person who assumed responsibility for the home care needs of the individual with advanced cancer and was not paid to do so” (Cameron et al., 2004, p. 139). Family caregivers are the lay persons primarily involved in the patient’s care (Oldham & Kristjanson, 2004) not being professionals, or “a carer or support person, e.g. a spouse/partner, other relative or friend” who gives physical and/or emotional support (Burns et al., p. 489). Family caregivers are sometimes called “hidden patients” (Kristjanson & Aoun, 2004, p. 359), as their sufferings at times are neglected.

A palliative home care team had the main responsibility for the son’s care during his last weeks. A high level of medical interventions that must be carried out by professionals was needed and administered. The family members regarded themselves foremost as a wife, a mother, a mother-in-law, a sister and a brother and secondly as caregivers, who took part in the daily palliative care. The three-year-old daughter in the family helped out as best she could. The family members were lay caregivers, implying that they did not have any
education in the palliative field, but had to be guided by the nurses in the palliative home care team.

**Dying and death**

As soon as we are born we are proceeding to our death, an existential dilemma to most of us. In palliative care the question of when a patient is labelled to be dying requires an answer, as this advanced care is primarily aimed at helping those who are facing an impendent death. The labelling process involves a decision by a medical professional that the patient will die. A rule of thumb to predict the time of death is to estimate the change in the patient’s state. If there is a noticeable change for the worse over a period of months then death will probably follow within a few months. If the change is weekly—then the patient might survive for a number of weeks (Twycross, 1995/1998).

In a longitudinal study on patients with advanced cancer four time sequences were identified to capture the trajectory to death: the palliative phase of the last six months of life; the advanced phase of one year from death; the serious illness phase of 1–2 years from death; and the chronic disease phase of more than two years from death (Burns et al., 2004). Yet another way to express the time between terminal illness diagnosis and death is the “living–dying interval” (Mystakidou et al., 2005, p. 835).

In this study the process of dying, the son’s trajectory to death, is defined as about seven weeks during which he received palliative care, despite the fact that the mother had realized much earlier that there was no cure for her son and the son himself disavowed that he was dying until about a week before he died. The reason is that during these weeks a palliative home care team was involved in his care. The word death will be used for the ultimate endpoint of the dying trajectory.

**Grief and bereavement**

In 1975 there were 27 listings of grief in articles on grief in The handbook of Social Psychology compared with 42 in 1980 and 107 in 1990, indicating that psychologists have taken a greater interest in grief during the last decades. In 1961 Engel suggested that grief itself was like a disease (in Averill & Nunley, 1993). The reasons why grief should not be classified as a disease are that society does not consider grieving persons to be sick, normal grieving can be distinguished from clinical depression, and uncomplicated bereavement is not classified as pathological in the American Psychiatric Association’s Diagnostic and Statistical Manual (DSM III-R) (Averill & Nunley, 1993).
In contemporary literature on grief and bereavement there seems to be some but not total consensus on the definitions of grief, bereavement and mourning. Bereavement most often refers to the state of having lost a loved one by death regardless of the emotional reaction to the loss; grief refers to the person’s reaction to the loss, and is most often measured by the psychological symptoms connected to it (Kreichbergs et al., 2004). Mourning refers to the family, religious and cultural rituals through which bereavement and grief are expressed (Cohen & Mannarino, 2004). Parental grief relates to the loss of a child by death.

Another way to distinguish bereavement from grief is presented by Attig (1996), claiming that bereavement happens to someone and over which a person has no control, whereas in grieving a person actively relearns relationships to self, to other persons, and to the external world (Balk, 2004). Attig (1996) stresses the choices human beings have in their bereavement, and a subtitle to his book on grief is “Relearning the World”.

Even if there is some notion that grief could also be the reaction to such an event as the braking up with a boyfriend (Sparling, 2004), in the present study grief is used only in relation to death, implying that anticipatory grief is not a concept used to describe the mother’s experiences before her son’s death.

As mentioned, new models of grief emphasize on parents holding on to their relationship with their dead children in contrast to traditional models, that emphasize on bereaved people letting go of their emotional relationships with the deceased (Davies, 2004; Moules et al., 2004). The concepts of death, grief at large, and anticipatory grief will be elaborated on later.

Support
Interventions from family members, professionals, friends or others that according to the mother’s experiences helped the son and his family to cope during his trajectory to death, and during the mother’s grief and bereavement are considered in the study as supportive. Communication that made a positive difference to the mother is thus supportive.
METHOD

In this chapter the data collection and data analysis are described and discussed. Some comments are given on diaries as data. The use of narratives, their construction and the interpretation of them in earlier research are commented on. Finally a rather hands-on-description of the steps in the data analysis is presented.

Data collection

“There is a growing body of literature in psychology, philosophy, and the natural sciences that has acknowledged the value of narratives” (Dhunpath, 2000, p. 547). Since some decades narratives are acknowledged as scientific data in many fields of research.

There is a move towards the capture of the lives of ‘ordinary’ people, through historical projects, which assumes that all lives are intrinsically interesting, and challenges the orthodoxy that autobiographies should be produced by important people. (Haynes, 2006, p. 403.)

However, “the role of memory and metaphor in the creation of meaning in personal narratives has not been sufficiently explored in nursing literature” (Gaydos, 2005, p. 254). In the article on his own fear of death after having a brain tumour, Craib claims that it is absurd “that we should try to assess people’s fear of death by asking them questions about it” (2003, p. 289).

The point of assessment would have to be a moment of confrontation with death, before the defences arise. … If everything within the personality tries to escape from an emotion, a researcher with an interview schedule is not going to draw it out. (Craib, 2003, p. 289.)
This might be relevant also to the mother’s fear of her son’s death in this study. The mother kept a diary almost on a daily basis, from the day of the diagnosis of her son till his death. In her diary she was able to spell out her fear and despair of her son’s death. This kind of data would not be possible to collect retrospectively. However, her diary was not a data collection in a scientific way of speaking and when it was written she had no intention to use it in a future scientific context. It was kept during her son’s trajectory to death as a means to deal with life in an extremely challenging situation. It was a way for her to remember fear and devastation, to be dealt with later. In her diary she could express the fear and despair that she did not dare to verbally articulate. Her diary is used as raw data in the study. Not before a year after her son’s death did the mother read her diary.

Health diaries have been common in nursing practice settings, e.g. as a means for clients to document their symptoms. However, such diaries have only been used sporadically since the 1950s as data collection methods in nursing research (Richardson, 1994). In sociological and psychological research diaries, intimate journals people keep for their own personal purpose, have since long been used (Allport, 1942). The advantage most often put forward for using diaries is that they can give rich data on an individual level (Richardson, 1994). Another is that in a diary experiences can be registered whenever and wherever they are made.

Literature often tells about diary keepers or narrators who find telling about experiences helpful in coping with different kinds of suffering, even if it may in the short term perspective cause anxiety (Carlick & Biley, 2004; Richardson, 1994). “Patients offer their personal stories in exchange for care” (Gaydos, 2005, p. 254) is one way of expressing the benefit of story-telling in caring. Narratives are becoming a more important component of health care’s drive to be more humane and holistic (Carlick & Biley, 2004). In a review of narratives written by people facing death from cancer and other diseases the insights that narratives offer are described as invaluable as they reveal the patient’s experience of care, and give an opportunity to study changes over time (Bingley et al., 2006) and prominent in that the voice of the individual experience has a resonance (Small, 1998). It is up to the researcher as also an autobiographer to let the individual experiences resonate in a framework of contexts and theories.

When her son had died the thought had struck the mother that her granddaughter, who lost her father, would eventually want to know what happened to him during his illness. The mother started to write to her granddaughter
about her father’s trajectory to death. It has been shown that children can spend years trying to find out why and how a parent died (Falk & Lönnroth, 1999), and the writings were thought of as a source from which the granddaughter could gain information in the future. As it turned out, the writings were more about the son’s life than his illness and death, and they developed into a private book not only about the son’s palliative home care and life but also about the mother’s experiences of being a parent in grief and bereavement, and of the support given to her. These retrospective writings are more elaborate than the diary. Still they are impressionistic. They were not aimed to be used in a study when written, but now they are the second source of raw data. This by no means implies that the raw data is not constructed. In addition other notes, e.g. calendars and timetables, are used to confirm dates of events.

The writings are subjective and non-systematic—all violating demands for research in a positivistic paradigm. On the other hand they might have a potential to “explore socially and personally constructed realities” and to “add depth to the assessment of the grieving process” (Stroebe, Stroebe & Schut, 2003, p. 238). Of course they do not provide a perfect account of what happened (Herman & Vervaeck, 2005).

In all, the diary consists of 11812 words and the impressionistic writings of 20126 words. In the forthcoming the diary and the impressionistic writings will be named writings, even if their origins differ. The writings are used to construct narratives that are personal and “give shapes to life experiences” (Gaydos, 2005, p. 255). They have a narrative character, in the sense that they are “the semiotic representation of a series of events meaningfully connected” (Herman & Vervaeck, 2005, p. 13). Three modes of distinguishing discourse for recounting events are; annals, representing events as temporally ordered, chronicles, representing temporally ordered events pertaining to a single subject, and narratives, which require some additional connection among the events, e.g. causes and effects (Velleman, 2003). The causal content of a narrative underlies its explanatory potential (Carroll in Velleman, 2003). Some of the excerpts from the mother’s diary as well as from the impressionistic writings that are included in the study divulge events that describe causes and effects and can therefore be categorized as narratives.

There is no consensus concerning the definitions of narrative and story in the literature. Not until 1979 was narrative introduced as a descriptive term in the CINAHL (Carlick & Biley, 2004). A number of denominations have been given to the unfolding of one’s life; personal narrative, self story, personal
story, life story, life history and life journey are some expressions (Gaydos, 2005). In Figure 1 some examples of definitions of narrative and story are given.

<table>
<thead>
<tr>
<th>Source</th>
<th>Definition of narrative</th>
<th>Definition of story</th>
</tr>
</thead>
<tbody>
<tr>
<td>CINAHL</td>
<td>An account of events experienced by the narrator</td>
<td>Repeated telling or reading of a story by persons other than the narrator</td>
</tr>
<tr>
<td>Steffen (1997)</td>
<td>Personal narratives are characterized by their focus on the individual experience of specific events and in this sense accounts of the unique</td>
<td>The story is characterized partly by its focus on individual experience and partly by its historical structure</td>
</tr>
<tr>
<td>Eaves, McQuiston and Shandor (2005)</td>
<td>Narrative is a meaning structure that organized events and human actions into a whole</td>
<td></td>
</tr>
<tr>
<td>Ellis and Bochner (2000)</td>
<td>A first-person account, written as a story that expresses vivid details about the author's own experiences</td>
<td>The research text is the story, complete (but open) in itself, largely free of academic jargon and abstracted theory</td>
</tr>
<tr>
<td>Frid, Ohlén and Bergbom, (2000)</td>
<td>The written or spoken expressions of a person's lived experience</td>
<td></td>
</tr>
<tr>
<td>Haynes (2004)</td>
<td>… narratives, that makes up people's stories … my experience and those of others, and to the expression of that experience in stories, or narratives…</td>
<td></td>
</tr>
<tr>
<td>McNay (2000 in Haynes, 2006)</td>
<td>Narrative is a universal feature of social life: it is the fundamental mode through which the grounding of human experiences in time is understood</td>
<td></td>
</tr>
<tr>
<td>Wiklund, Lindholm and Lindström (2002)</td>
<td>A narrative is not an objective reconstruction of life but of how it is perceived</td>
<td></td>
</tr>
<tr>
<td>Murray (2004)</td>
<td>Narratives … refers to the stories we develop and discover in our own lives and in our interaction with others</td>
<td></td>
</tr>
<tr>
<td>Thompson (1996)</td>
<td>Narrare, an account of connected events, a story</td>
<td></td>
</tr>
<tr>
<td>Paley and Eva (2005)</td>
<td>Narrative is a reported sequence of events</td>
<td></td>
</tr>
<tr>
<td>Polkinghorne (1995)</td>
<td>Narrative is the type of discourse composition that draws together diverse events, happenings, and actions of human lives into thematically unified goal-directed processes</td>
<td>I will use story, in its general sense, to signify narratives that combine a succession of incidents into a unified episode</td>
</tr>
<tr>
<td>Velleman (2003)</td>
<td>A story enables its audience to assimilate events … to familiar patterns of how things feel</td>
<td></td>
</tr>
</tbody>
</table>

**Figure 1. Examples of definitions of narrative and story**
Story and narrative are sometimes used interchangeably (Eaves, McQuiston & Shandor, 2005; Paley & Eva, 2005). Instead of the confusing term narrative, Paley and Eva suggests narrativity to be used, defined as “something that a text has degrees of” (Paley & Eva, 2005, p. 85), thus indicating a continuum between low and high degrees of narrativity. Figure 2 illustrates the degrees.

<table>
<thead>
<tr>
<th>Degree</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td>... ....</td>
</tr>
<tr>
<td>8</td>
<td>... and presented in a way that is likely to elicit an emotional reaction from the audience</td>
</tr>
<tr>
<td>7</td>
<td>... the explanation being related to the problem they confront</td>
</tr>
<tr>
<td>6</td>
<td>... characters who are confronted by some kind of difficulty or problematic issue</td>
</tr>
<tr>
<td>5</td>
<td>... there being one or more characters centrally involved in the events described</td>
</tr>
<tr>
<td>4</td>
<td>... causally related in such a way that a certain event is explained</td>
</tr>
<tr>
<td>3</td>
<td>... two or more events, some of which must be causally related</td>
</tr>
<tr>
<td>2</td>
<td>The recounting of at least two events</td>
</tr>
<tr>
<td>1</td>
<td>The recounting of one or more events</td>
</tr>
</tbody>
</table>

An account that incorporates features 1–3 is a narrative and an account which also incorporates features 4–8 is a story, according to Paley and Eva (2005). This scale is not a perfect fit with the original writings in the present study. They are “the rehearsals of a series of events, incorporating claims about how they are causally connected—about what lead to what” (Paley & Eva, 2005, p. 91), but they have also proven to “elicit an emotional reaction from the audience”, step 8 in Figure 2, whereas they do not always give explanations of the encountered problems, step 7. Explanations will be given in the interpretations and contextualization of the narratives that are constructed from the writings.

**Data analysis**

The data analysis started when the mother a year after her son’s death read her diary kept during her son’s palliative care to identify events of communication that were experienced as supportive to her.

To express experiences in a narrative is a process, where fragments are linked together and confusing personal experiences become a coherent narrative. This process is partly introspective and an individual meaning is created (Steffen, 1997). The process calls for a structural analysis of what is experienced and told in interviews or as in this study in the mother’s writings. There is a difference between “storying experience of others phenomenologically and
narratively reconstructing experience through stories that include the researcher’s autobiography” (Lindsay, 2006, p. 44).

In constructing the four narratives included in this study the attempts to be faithful to the mother’s experiences and feelings as they are formulated in the writings are prioritized. The narratives are never the less retrospective constructions. The diary captures the experiences in very short retrospect, sometimes a few hours. The impressionistic writings, on the other hand, were made at a later date after the experiences, and are more elaborate. Most of them have a higher degree of narrativity than the diary. This implies that descriptions have been included in retrospect in the narratives built on the diary to connect the events. As Haynes writes (2006, p. 411):

Indeed as I write the account, I re-experience the events and feelings described through a filter of time, memory, and reflection …

A five step analysis was used by Eaves, McQuiston and Shandor (2005, pp. 144–145) in their narrative analysis. Five questions were asked:

• What is this story about?
• What takes place in the story?
• What are the social meanings and actions of the story?
• How are cultural values expressed in the narrative?
• How do cultural values structure and integrate individual experiences?

The mother’s writings also included accounts not within the studied area. A first step in the data analysis was therefore to identify events including experiences of communication that had a positive impact on the mother. These events were arranged chronologically. This process might be seen as a naïve interpretation (Wiklund, Lindholm & Linström, 2002) or, the first step in emplotment, i.e. the way events are combined into a particular story, thus specifying a problem (Polkinghorne, 1995). The two first questions, according to Eaves, McQuiston and Shandor (2005) were then addressed in the first step of the data analysis. The identification of significant concepts was included in this step (Figure 3). In a second step four narratives were constructed to illustrate these concepts i.e. the mother’s experiences were narratively restructured.

The remaining questions according to Eaves, McQuiston and Shandor (2005) are issues that are analyzed in interpretation. The narratives will be interpreted
in relation to theories on death, dying, grief and bereavement (step three, Figure 3). The four interpretations as a whole are thought of as an overall story, covering a time space of four years, from the diagnosis of cancer of the son till three years after his death. This comprehensive story is contextualized in the framework of social, institutional, family and personal contexts in which it is constructed (step four, Figure 3) (Goodson & Numan, 2002; Goodson & Sikes, 2001). The mother’s pre-conception and pre-understanding were expanded by the contextualization that added new dimensions (Wiklund, Lindholm & Lindström, 2002) to her understanding of her experiences of communication.

By contextualizing meaningful events however, personal narratives contribute to the understanding of individual experience as part of general social relations and cultural values, making them useful as cultural data in general. (Steffen, 1997, p. 99.)

It is crucial not only that a biography is located (Goodson, 1992, 1997), i.e. related to an individual, community and institutional context (Dhunpath, 2000) but is also put into theoretical contexts (Goodson, 1992) and linked to “wider narratives about social change and globalisation” (Goodson & Numan, 2002, p. 272). These kinds of contextualization aims at prompting “a wider awareness of the social influences on psychological and emotional life and the extent to which our personal responses to fateful moments are governed by the spirit of our times” (Seale, 2003, p. 390). The interpretations of the narratives introduce “a certain kind of organization and, correspondingly, a certain kind of purpose” (Paley & Eva, 2005, p. 91). As stories they have two levels of explanation, one is casual or representational, the other is emotional or affective (Paley & Eva, 2005).

The temptation to be self-serving is never far away in first person narratives, “where the I is the protagonist” (Paley & Eva, 2005, p. 92). A story will no doubt be subjectively persuasive as that is the point of stories. However

There is no methodological need for us to ‘believe’ narrative accounts such as those derived from interviews, any more than we are enjoined to reject them out of hand. Equally, there is no methodological justification to believe narrative as a form in itself. (Atkinson, Coffey & Delamont, 2003, p. 140.)

A theoretical framework can also be used as a context that enables the autobiographer “to preserve the credibility of his/her artistic endeavour without
constraining the fertile imagination form discovering its limits” (Dhunpath, 2000, p. 546). Hence, a theoretical framework may serve as a means of validation.

Validating an interpretation aims primarily at underpinning its credibility, not to exclude all other interpretations. Regardless of the subjective dynamics of a story and a seemingly coherent plot, the narrative’s claim of casual connection can still be true or false. “We should not allow subjective coherence to seduce us into forgetting that” (Paley & Eva, 2005, p. 94). Narratives are not sacred (Craib, 2000). However, if the research product, e.g. a story, “is well sign-posted, the readers will be able to travel easily through the worlds of the participants and makers of the story and decide for themselves whether the story is a legitimate research endeavour” (Koch, 1998, p. 1182). The intention is that the narratives in the present study are “well sign-posted” enough to give the reader a possibility to scrutinize how they have been interpreted.

Pragmatic validation is sometimes suggested in narrative research. The narratives included in the study have been read by the son’s family members who were involved in his care, the nurse who had the main responsibility for the son’s palliative home care, the mother’s family doctor (except the narrative on intergenerational communication). Excerpts from the narrative on “Words that made a difference …” have been orally told to the members of the mother’s parent bereavement group, who shared some of her experiences. The mother’s friend, who is mentioned in the same narrative, as well as other friends have also read the narratives. All readers recognized events in the narratives, according to their knowledge.

According to Glaser the accuracy of a qualitative data analysis has many synonyms: credibility, trustworthiness, auditability, validity, objectivity, verifiability, reliability, reproducibility, evidentially, factually, etc. (Glaser, 2003). Indeed a “criteriology” has been developed (Seale, 2001, p. 134). The words are not completely synonymous, and all but two, objectivity and reproducibility, would be applicable to the analysis in this study. Yet another word could be added to the list of Glaser’s “accuracy-words”, namely justifiable. The justification of knowledge that in a positivistic tradition is legitimized by relating to grand theories is altered to concern also justification through the pragmatic value of the knowledge (Kvale, 1997). It is not possible to pragmatically justify the value of the study until the results are published. However, some indications were given by the nurses in the palliative home care team, who invited the mother to share her narrative on her son’s palliative care at a seminar at the
unit for palliative care at the university hospital. The nurses claimed that her experiences as narrated in the published articles contributed with useful input to the area of palliative care and were in this manner being validated by members of the field, as in a grounded theory approach (Glaser, 1998).

Guba and Lincoln (1989) discuss three different approaches in relation to constructivist inquiry; the trustworthiness criteria, criteria considering the unique contribution made to goodness, the nature of the hermeneutic process itself and the authenticity criteria. The issues of credibility, transferability, dependability and confirmability are features in the trustworthiness criteria, to which more conventional concepts are related. Credibility includes reviewing by peers who have no interest in the research report, and a search for negative instances. Peer reviews preceded the publication of articles (Holmberg, 2006a, 2006b, 2007a) based on the narratives before they were published. By providing a detailed, rich description of the settings in which the study is conducted transferability might be possible, that is to give readers the possibility to make their own judgements of the findings. Such descriptions are given in the narratives and are complemented in the interpretations of them. Dependability is achieved through e.g. auditing, that is to involve other researchers examining the research process as well as the product and it replaces the concept of consistency or reliability. Auditing may also contribute to confirmability. In discussions in seminars the articles have been scrutinized and some valuable input has been integrated into the study. This kind of discussions is more valuable than concordance between researchers as disagreements can provide alternatives to the interpretations (Barbour, 2001).

Guba’s and Lincoln’s (1989) criteria are formulated in relation to evaluation, in which there are specific stakeholders to feed the result back to. This is not the case in the present study. Instead the analysis implies that theories in the field of and research in palliative care, grief and bereavement are fed into the interpretations. As the narratives cover a time span of four years and the mother started to read and learn about palliative care, grief and bereavement a year after her son was dead, theories in that area also influenced her interpretations during the analysis process. Interpretations were made and remade in an abductive way according to input from earlier research. The picture of walking between empirical data and theoretical constructions (Alvesson & Sköldberg, 1994) well illustrates the process.
The third criteria, the authenticity criteria, includes among other things fairness, an issue that will be further discussed in a final chapter. After all, in research on qualitative data “presentation of evidence to support claims depends largely on trust, for it is done by means of summary impressions by the authors” (Seale, 1999, p. 196). The balance between reliability and validity is not only an issue related to research on palliative care, grief and bereavement, it is an issue for research at large. A parallel might be drawn to the interpretation of quantitative data.

Hence, what is to be validated is not the test or observation device as such but the inferences derived from test scores or other indications—infences about score meaning or interpretation and about the implications for action that the interpretation entails. (Messick, 1989, p. 13.)

The interpretation of the narratives opens up for re-interpretations, as does a grounded theory in a grounded theory approach. Examples are given by Seale (1999), when he tries to pursue the possibilities of a different reading in studying the classical work on awareness of dying by Glaser and Strauss (1967) in 30 years hindsight, from a position that is partly outside the original authors’ paradigm, or when he analyses Craib’s article on fear of death (Seale, 2003).

The data analysis in the thesis can be described as consisting of the identification of significant events and important concepts in the writings, construction of narratives, and the interpretation and contextualization of the four narratives. In a fourth step the overall results of the interpretations are summarized and discussed in a broader contextual framework of dying, death, grief, bereavement and reconciliation. A description of the separate steps is given to illuminate the process of the data analysis. In reality the steps were not clearly separated. In a hermeneutic-like process the writings were read and re-read, the concepts emerged not once and for all, the interpretations of the narratives were adjusted according to the mother’s reconciliation process, specific and general learning and general development through “cycles of interpretation, thinking contextually and hermeneutically—re-interpreting themes and patterns” (Diekelman & Ironside, 1998 in Lindsay, 2006, p. 39). Being an educationalist the mother as a researcher (and as a mother) believes that people, even researchers, learn not only from education but from life at large.
Ethical considerations

Approval to carry out this study was granted by the patient’s family, that is his wife, sister, brother and mother-in-law. Written consent to the study was given by the nurse who had the main responsibility for the patient’s palliative home care team, the palliative home care physician and the deputy head of the palliative care department at the university hospital, to which the team was connected. Approval of the study was also given by the dean at the mother’s department and the secretary of the Ethical Committee at the university to which the mother was affiliated.

Summing up

From a diary during the son’s palliative care and impressionistic writings during three years of grief and bereavement four narratives were constructed in retrospect. Contents in the writings that indicated experiences of communication that had a positive impact on the mother during the four years were identified and retold in the narratives.

Narratives are becoming a more important component of health care’s drive to be more humane and holistic (Carlick & Biley, 2004). Narrative analysis is said to constitute “a challenge to the prevailing logistic view which underlies the technical rationality” (Elbaz-Luwisch, 1997, p. 77).

In North America, the number of researchers doing narrative work seems to have reached a “critical mass”, and narrative researchers do no longer need to argue for the legitimacy of their methods with every new study. In smaller countries the academic community is likely to be more cautious and conservative. (Elbaz-Luwisch, 1997, p. 77.)

Sweden is a small country and arguments for using narratives in this study were given in the discussion of the approach. Some more will be put forward in the forthcoming. In a thesis there is a need to clarify methods transparently to qualify the results and make them open to an academic discussion, and a stepwise description of the process of data analysis can be motivated. Below the four steps in the analysis are summarized and the study is placed in a time perspective (Figure 3 and Figure 4 respectively). The titles of the articles that are published in relation to the study are given.
Step 1: Identification of significant events and important concepts in the writings

In the mother’s writings events were identified, that were related to experiences of communication in palliative home care between the mother and her dying son, between the palliative home care team and the son’s family, and in support during the mother’s first years of grief. In these events concepts emerged, that were related to positive significant meaning of the communication to the mother.

The concept of significance is problematic. The mother decided on what were concepts of significance. The mother’s pre-conception as a mother, as a lay palliative caregiver and grieving parent have naturally influenced what concepts seemed to have importance for her also as a researcher. Furthermore her pre-understanding of behavioural theories had an impact on her reading of the writings. Literature in the field of palliative caring and thanatology also influenced what concepts the mother as a researcher chose to use in the further analysis.

This is not exceptional for analysing autobiographies. The researcher’s pre-conceptions and pre-understanding always influence the research process, from the choice of research area, to the choice of approach, methods for data collection and data analysis and so forth, all of which are dependent on the researcher’s ontological and epistemological standpoints.

Step 2: Construction of narratives on experiences of communication

The concepts that emerged and seemed to have importance for the understanding of the mother’s positive experience of communication formed a framework for the construction of narratives. Events illustrating the concepts were arranged in a time order into narratives, to reveal the contents in the communication and what happened in the communication, according to the mother’s experiences. The narratives contain rather detailed excerpts from the writings to illustrate the concepts, in order to invite the readers to be a co-interpreter of them.

In some cases memories and descriptions of the settings, not appearing in the writings, are included in the narratives, to make them illustrative. The narratives are constructions, as are the writings, but on a more conscious level. Making the concepts transparent to an audience is a means of revealing to others the effects of the communication, according to the mother.
Yet one more point must be made. The construction of the narratives based on the concepts that emerged when reading the writings some years later implied that the constructions were made not by the mother in grief, but by the mother as a researcher. The writings were made by a mother to a dying son and a mother in grief but analyzed by her as a researcher. However, even if she focused on the researcher’s role in constructing the narratives, she sometimes lost the scientific focus, had to put her data away, weep for a while, and be a mother in grief. To be emotionally moved by observations or other data could be seen as an obstacle for the research process, but also as an advantage.

**Step 3: Interpretation and contextualization of the narratives**

In a third step questions were asked about the ascribed meanings of the actions and events in the narratives. The narratives were related to research on palliative care and parental grief and bereavement. Such a measure is used to put the study into an area of related frameworks to validate the findings. The mother’s experiences of communication as such do not have to be justified in the research literature. Her interpretation of them, on the other hand, is just one of many possible interpretations. By relating the findings to other studies in the area of palliative care and grief and bereavement, the credibility of them can be studied.

**Step 4: Contextualization of the overall findings**

Implicitly a case strategy points to a belief that situational factors have a direct effect on the phenomenon being studied. Research on how and why contextual factors have influenced the narratives and the interpretations of them is needed (Walshe et al., 2004). In the last step of the analysis the interpretations of the four narratives were located in broader contexts of dying, death, grief and bereavement in a contemporary Swedish society and related to empathy.
Figure 3. The steps in the data analysis. (Two of the four narratives are included in the figure. (E=Event, C=Concept, N=Narrative, I=Interpretation and BCont=Broader contexts)

In Figure 4 the study is presented in a time perspective.
**Figure 4. The study in a time perspective**

*Below the titles of the articles are given:


IV Holmberg, L. (2007b). Intergenerational communication: Shared loss. (To be submitted for publication.)
In the next four chapters the narratives are presented and interpreted. Each interpretation is introduced by a very brief description of the background setting, including the concepts that are illustrated by the narratives. The chapters are named according to the main contents in them. Again, a reminder about the narratives and the interpretations will be given: they are based on the mother’s experiences. What is said about the son, the other family members, the nurses etc. is all from the mother’s point of view. Not to cause too much disturbance to the readers when it comes to the language and to avoid disturbing repetitions this is not always explicitly reproduced in the coming texts.
HOPE AND DISAVOWAL VERSUS FEAR AND DESPAIR

Introduction

First, a brief remark on the heading of this section: The words fear and despair are used to describe the mother’s state of mind from the time of her son’s diagnosis to his demise. It is not possible to say when fear was transformed into despair, nor when despair caused fear. Other words could have been chosen, e.g. devastation and horror.

The son was sent home from a university hospital about seven weeks before he died with a box of chemotherapeutics indicating that he was under cure. However, the mother did not believe the cure would help her son to survive.

A “cross-generational coalition” (Werner et al., 2005, p. 500) was established in the son’s family between the son’s wife, his mother, and his mother-in-law. His wife was the head of the lay home care. The son needed care around the clock. His wife and his mother took turns sleeping. The son’s mother-in-law took on a substantial part of the care of their by then three-year-old daughter.

The communication between the mother and her son changed. From being a friend in a relationship between two equal adults before he was ill, the mother became like a carer for a small child. Their communication was mostly about practicalities. The mother felt insecure and uncomfortable. She tried to shelter her son from her sad thoughts. Her son explicitly told his mother that he did not want to talk about negative scenarios.

Not until a palliative home care team was involved in her son’s care did the mother see a possibility to talk to professionals about her greatest fear; that her son was dying. The palliative home care team recognized the mother’s fear and despair and acknowledged that her son was dying. The nurses and the doctor
in the palliative home care team talked to her in a way that the nurses and doctors at the hospital, where her son was treated and where he had had surgery, did not.

Not until the effects and side effects of the chemotherapy were explained by the physician and the nurses in the palliative home care team to the son in an intellectual and non-persuasive way did he realize that he did not have very much time left to live, and that this time would be better without chemotherapy. Only then, about a week before he died could he and his mother share profound sorrow. Their communication once again became open, warm and close.

The mother’s experiences of the communication between her and her son as captured in the diary and retold in the narrative are analyzed in a time perspective and related to the support from the palliative home care team. The first three phases of the son’s trajectory to death are described briefly to give a background to his palliative care, phase 4 (Figure 5). Again it must be stressed that the narrative is constructed out of the mother’s writings and interpreted by the mother as a researcher.

The son’s hope and disavowal and the mother’s fear and despair emerged as important concepts in understanding the communication between mother and son during his trajectory to death. The interventions from the palliative home care team that supported the mother might be summed up as

- recognizing and acknowledging the son’s hope and disavowal and the mother’s fear and despair
- respecting the son’s and the mother’s integrity.

For the team to prioritize the son’s hope and at the same time recognize and respect the mother’s fear and despair called for professional experience. Besides giving advanced palliative medical care to the son the team also provided emotional care to the mother as a caregiver.
In Figure 5 the time scope of the son’s trajectory to death is illustrated.

![Diagram showing the trajectory of a son's death with phases and timeline]

**Figure 5. The son’s trajectory to death in an approximate time perspective**

**A narrative on communication. A dying son and his mother**

**Phase 1: From diagnosis to the first surgery**

When we came to the hospital [in the middle of the night] my son was sitting on his bed. My son had lost 12 litres of blood. A very complicated surgical operation. The entire main tumour was removed in one piece, according to the surgeon. The metastases were taken away. No visible cancer was left. His liver seemed intact.

No guarantees however. In my son’s favour is that he is young and healthy /if it were not for the cancer/.

His wife went home about three o’clock in the afternoon. By then the analgesics seemed to be working.

My son and I had some good hours. We talked about that

- he was happy that his brother and sister were supporting him
- fortunately we went to the hospital on the 5th of October
- his daughter does not care if her father has one or two bags on his abdomen
- he is a fighter
- he had been worried about not waking up after surgery.

We talked about a lot of other things too. We were close. We held hands.

---
Now I am lying in the guest room [in his house], where my son spent many sleepless painful nights.
We will overcome this! We will! (21/11 2002)

Phase 2: From the first to the second surgery
I knew my son was a fighter. But I had read some articles on leiomyosarcoma and my family doctor had told me about the seriousness. My hope was fading. But I did not dare to show it to my son. The wordings “We will overcome this. We will”, should be seen more like a magical utterance to abort the illness than an expression of hope.

On the 30/11 my son wanted to leave the hospital supported by his wife. They both wanted to have a family life at home as soon as possible. I wrote:

Now I am worried again. What if my son does not complain emphatically enough [about a terrible headache]. He and his wife want him to come home tomorrow. I do not think he should leave the hospital. I think he is too tired and I am worried about the headache. I think it is better his daughter comes to the hospital and visits her father. It is a dilemma. (30/11 2002)

This is the first time I explicitly write about a dilemma. I wanted my son to be cared for at the hospital for a longer time. He wanted to live a family life as soon as possible. On one hand I supported him wholeheartedly in coming home, on the other I wanted him to be safe. I was scared and even if I recognized my son’s fighting spirit I thought only a miracle would make him survive. And I do not believe in miracles.

I am worried all the time—about details as well as about larger issues. (1/12 2002)

Nobody at the hospital had explained to me in private about my son’s illness. Nobody had mentioned the word death, a word that was in my mind all the time. In my mind my role as a lay palliative caregiver began to take form at the onset of my son’s fight against his cancer.

The word sarcoma has a paralyzing effect on those who understand.

I can’t talk to my daughter-in-law nor to her mother about my worst worry: What if the oncologist tells us, that there is no chemotherapy for this type of cancer? These days are terrible. (5/12 2002)
My son recovered from his first surgery. His headache decreased. Christmas time was close.

We must allow ourselves to be a little happy in between. Embrace the good days. Life will never be really safe again though. (8/12 2002)

I felt as if I walked a tightrope. I wrote in my diary but I did not dare to pronounce my fear openly in the family.

My little son—now you should have a positive surprise. You are worth it!

Now it is time for you to have some good news and no more disappointments. You have been tried enough and you have suffered enough.

But—as I have thought several times during the past month—life is not fair! (10/12 2002)

From being a friend in a relationship between two equal adults, it was as if I more and more became like a mother to a small child, trying to shelter my son from my sad thoughts. I felt insecure and uncomfortable. My son was focused on defeating his cancer. He did not want to talk to me about the fact that the tissue margins of the “child-head-sized” (the surgeon’s wordings) tumour, that was removed from his abdomen, were not completely surgically excised. He just waited to start his chemotherapy as soon as possible. My son explicitly told me that he did not want to talk about negative scenarios. As an elite athlete, he told me, he had learnt to concentrate not on the opponents’ scores but about the scores he was yet to achieve. Now he did not want to talk about the eventuality of losing the match against his cancer.

However some good news came. A chemotherapy was planned. But still I could not fully share my son’s commitment.

He is very optimistic. I really have to put a lid on my anxiety. I see a troublesome year in front of me. If only it leads to something good we will cope. (4/1 2003)

My son started to work part time during chemotherapy, and family life was slowly coming back to normal. He began to exercise to regain his muscles and physical strength, but I saw my son losing weight and his hair falling off.

Pray all will lead to something good. (17/2 2003)
When summer came we spent some time together “as it was before” by the beach in my summer house, my three children, their spouses and the six grandchildren. During summertime my diary was more like an agenda. It was easier for me to pretend, when the sun was shining, the grandchildren swimming in the sea, and the steaks were grilled. However, when a photograph of us was taken, I thought: This is the last picture where we are all together.

In the beginning of August I wrote:

  Everything has proceeded according to plan. We got used to the chemotherapy, i.e. we watched how my son with energetic determination let himself be treated. In between most chemotherapy treatments he worked part time.

  It is difficult. My son is so silent. I feel as if I tip-toe around him. I do not know what is best. Should I disclose to him my worries? If he is worried too, we could share our worries. But to awake anxiety in him is not good. Worries you can share—anxiety you can’t.

  Now his abdomen and back hurt again. He has had his lungs X-rayed and nothing pathological was found. He is due to have an X-ray on his abdomen in about a month.

  I think he looks exhausted. He says he feels exhausted. His stomach is swollen. However the surgeon calmed him down.

  I more and more feel we must talk to each other. Now I just talk about my son, mostly with his mother-in-law. Tomorrow I will talk to C [a friend who is a psychologist] to get some advice on what to do.

  In a way I am preparing myself mentally for times of horror. Intellectually I know that it is a waste of time. It would have been better to be happy for what is good now and keep the energy till horror comes. I think I need somebody to talk to.

  Remarkably—it is as if I try to overpower my despair and horror by writing. Unfortunately I do not succeed. (16/8 2003)

**Phase 3: From the second surgery to the start of the palliative home care**

Now I can no longer try to write the horror away. My son is dying.

  ... the surgeon talked to my daughter-in-law and me about an uncertain outcome. “We have to catch him now”, he said. (30/8 2003)
My son had to have emergency surgery. A large tumour in his abdomen had blocked his small intestine. After surgery, he had 1,5 meters left, enough according to the surgeon and the oncologist, for a new spell of chemotherapy.

... wonder if it is of any use at all, but in front of my son and his wife I must pretend I think it is. In my best moments I try to hope, but deepest down I think he is dying. I do not understand. Pray he will not suffer. (31/8 2003)

Phase 4: From the start of the palliative home care to my son’s death
After about a month my son left the hospital to be cared for at home and a palliative home care team was involved in his care. At last I had the opportunity to talk about his impending death.

The palliative home care team supports, gives him intravenous drip and the nurses are there for us!

My daughter-in-law still hopes that the new chemotherapy will have some effect and so does my son. But I do not believe in it. I think my son is far too ill.

And ... he fights ... it hurts seeing. He is very very ill. I wish he had some peace. We are so powerless. (1/10 2003)

Encouraged by the palliative home care team all family life, that was ever possible, was lived—in waiting for death. Timing for pain relief and other medications were adjusted as well as possible to the rhythm of family life. For instance the drip in the evening was prepared by the nurses for my daughter-in-law to start, in order to give my son and her some time together after putting their daughter to bed. These hours were of course of utmost significance.

I usually went to bed very early. My daughter-in-law had bought an alarm device, that was installed in my son’s room. I and my daughter-in-law took turns having the alarm bell where we slept. As the device sometimes failed to work and I was afraid not to be there when needed I had difficulties falling asleep. And I did not really want to sleep.

One of my greatest horrors was to think about the moment of death. What would it be like? I was convinced it would be soon. When I got to know the nurses in the palliative team I asked them. They listened and explained from their experiences.
Finally a week before my son died he stopped his chemotherapy and started to prepare himself for death. The physician and two nurses in the team spent many hours on one specific day talking to my son, his wife and me. In the morning, we all sat on the floor, as my son could not sit on a chair. Before the meeting my son prepared a kind of a flowchart, showing the options of stopping the treatment. At the bottom, as an argument for continuing the treatment, he wrote (23/10 2003):

Chemotherapy:  + May have an impact on the cancer cells
               - If not taken, the cancer is terminal
               = Continuing chemotherapy in favour

Quality of life:   Negative without chemotherapy
                   All my values were all right!
Physique:        I am fine!!!

By that time my son was severely affected by the chemotherapy. He could hardly see, could not eat, and had difficulties speaking, as his mouth was sore. He knew beforehand that his wife would support him whatever he decided. Now he turned to me and asked about my opinion. I said that I of course supported him, whatever he chose to do. After about an hour he asked the team to leave, as he needed a rest and wanted to talk to his wife in private.

In the afternoon he, his wife, the physician, the nurses and I gathered again on the floor. The physician once more explained the side effects of the chemotherapy in an intellectual and non-persuasive way. My son was told that the chemotherapy did not have a chance to reach the cancer cells, as his small intestine was blocked by tumours. Key information was that the physician assured my son that he would never end up “as a vegetable”. The doctor told my son that his body was already working overtime. My son was told that he did not have much time left to live and that these last days would be better without chemotherapy. My son was in charge of the decision and finally made up his mind to stop the treatment.

Then, a week before he died, he and I could share devastation and despair.

I helped him type his last letter to his friends, in which he invited them to come and see him. He told them that they had to come rather soon. He contacted his lawyer to write his will. But foremost—he wrote a letter to his daughter, for her to read when she gets older.
In my diary I wrote some hours after he died about one of the worse than worst moments, when we shared our despair.

I wonder if the picture of my son’s despair will ever go away. He was sitting on his legs in the bathtub, showering his ostomies. He looked at his arms:

“Mammy, there is nothing left.”
I hugged him and said:
“No. There is not very much left.”
“No use to exercise any more.”
“No, no use to exercise.”
My son’s head bent down, drooped, his chin was shivering, he pursed his lips, he slowly turned his head from one side to the other.
Despair!
Such a despair you can not comfort, not even share. It is doubled when I see it. My hugs can not comfort it, my tears can not make it less.
Dear dear son. This was not meant to be! (30/10 2003, 03.30 a.m.)

Interpretation

Phase 1: Different levels of hope
In the first phase the son’s diagnosis overwhelmed and devastated the family. “Profound sadness and sense of shock” is another way of expressing the reactions prior to the death of a loved one (Dunne, 2004, p. 50). The son’s and the mother’s coping strategies were quite different. The son relied on his fighting spirit and was focused on surgery. The mother did not deep down, believe that her son would be cured. She felt increasingly lonely and did not at first want to communicate her despair to anybody, as it would have been akin to making the worst happen.

The communication between the son and his mother changed from being close, open and honest prior to the son’s illness into a communication mostly about practicalities. An invisible semi permeable wall was built, allowing practical matters to seep through to her son and keeping her despair on her side. At least that was what she wanted; although she knew that she most likely also communicated her despair to her son. In this first phase, the son’s hope and the mother’s fear and despair were barriers to their communication.

The fact that all family members do not maintain the same level of hope is shown in a study on patients and spouses. Four different social processes were found (Salander & Spetz, 2002):
1) the patient does not seem to be aware, the spouse is aware but pretends not to be;
2) both are aware, but the patient does not want to share; they drift apart,
3) both are aware, they do or do not openly talk about the gravity of the situation; nevertheless, there is a joint platform, and
4) neither patient nor spouse seems to be aware; they carry on living as before.

It seems likely that there are also different processes in the relations between other family members than spouses. In our case the first process would be applicable, i.e. the son seemed not to be aware and the mother pretended not to be until a week before the son died. There is however, to the author’s knowledge, no research on the issue concerning the relationship between the levels of hope of adult dying children and their parents.

Phase 2: Communication almost as usual
In phase two, after her son had his first surgery the mother, on her son’s request, often spent the night at the hospital and could take part in his care. This comforted her somewhat.

When her son recovered from surgery, the mother began to regain some slight hope. Family life was slowly coming back to normal and so was the communication between mother and son, although the mother still did not dare to talk about what occupied her most, the seriousness of the cancer. On the other hand, their need to talk about the illness decreased as her son recovered. The son was determined to beat the cancer and regain his physical strength. The mother was thinking of the internet articles on leiomyosarcoma she had read, the faces she met on the hospital ward, the atmosphere she felt when talking to the surgeons and the oncologist. She had read the unsaid words in the faces of the hospital care providers.

To patients who suspect but still hope, the state of uncertainty can be harder to bear than the certainty of the knowledge (Mystakidou et al., 2002b). This might also be relevant for a mother.

Phase 3: The son’s hope and disavowal and the mother’s fear and despair
In phase three, when her son had a relapse, the mother’s vague hope for a cure for her son faded away. The mother was horrified. Relapse is said to be more stressful than diagnosis (de Graves & Aranda, 2005). In a literature overview on death and dying Craib found practically nothing about fear and that
... those who do write about fear of death were putting forward simple hypotheses rather than complex understandings of the nature of human existence. (Craib, 2003, p. 287.)

The son’s back and abdomen began to hurt and after some weeks he was back at the hospital for a second surgery. Again the mother spent nights at the hospital. The son still relied on his fighting spirit and was determined to beat the cancer or at least fight for every month, week or day. He still hoped for a cure and denied that he was terminally ill. Terminally ill patients and their families are often referred to as being in denial of impending death (Zimmermann, 2004; Zimmermann & Rodin, 2004). Perhaps the word disavowal should be used instead of denial, according to Salander and Windahl (1999). They suggest denial be used for “resolute elaborations with perceptual disorders” (p. 273). Disavowal, on the other hand, does not a priori connect to psychopathology. However, as denial is used in the literature on palliative care it will be used also in the present study, to indicate defence against external reality, even if denial and along with it repression are directed against demands from the internal world (Salander & Windahl, 1999). In the literature on death and dying denial is also seen as a personal choice or right (Zimmermann, 2004). The son was doctorally prepared in biochemistry. Intellectually, he knew what was going on in his body and talked to the physicians about scientific matters related to his treatment. But although he intellectually realized the seriousness of his illness, for a long time he still denied (disavowed, according to Salander and Windahl, 1999) that he was dying. Hinton (1999) points out that the patients and the relatives face different threats and that can explain the discrepancies in acceptance. The patients may not seek so much information and have the option to continue to deny right to the end, whereas the relatives are facing the realities of an up-coming bereavement. “On the whole, a patient’s visible deterioration increased relatives’ acceptance more than the patients” (Hinton, 1999, p. 32).

Craib spells out a reason for denial:

... if we were to face fully the fact of our own extinction, our non-existence, we would go mad, lose our reason and I can remember moments when I felt very close to this. (Craib, 2003, p. 288.)

What punctuated Craib’s fear was support from family, friends and colleagues and conversations, which recognized the possibility that he could die, and that
he could talk about the practicalities. This did, however, not happen to the son till about a week before he died.

“Hope is a dynamic experience” (Benzein, Norberg, & Saveman, 2001, p. 117). It is also described as a conscious state of mind, that is central to life and oriented towards the future, and highly individual, developed out of the unconscious psychological and safety needs, as described by Maslow (1954/1987) (Cutcliffe, 1997). Hope can be seen as having three dimensions; personal spirit, risk, and authentic caring. These emphasize the interpersonal experience, blend the themes of credibility and comfort and seek a balance of maintaining hope and truth-telling (Borneman et al., 2002).

There is evidence that hope plays a role in the patients’ and families’ coping in palliative care, although studies on hope in family caregivers are sparse (Borneman et al., 2002). Thulesius, Håkansson and Persson (2003) introduced the concept of “the homeostasis of hope” in a simple algorithm: H=V x T, where H symbolizes the existential hope, that is the motivation and well-being required to live a normal, everyday life, V the value of every lived moment and, T the expected time to live. This formula for hope seems to the mother hard to apply to the son in this study. His motivation to live and his fight for survival did not decrease until he realized that it was impossible for him to be cured. His motivation to live was not related to his perceived well-being. In the son’s case, the concept of hope seems to be more related to a motivation to live, even if life was not a normal everyday life. His hope cannot be understood by a simple combination of the value of every lived moment and the expected time to live. His hope was founded in his belief that he would survive. He was motivated and wanted to live any life but that of a “vegetable”. Perhaps the concept of the homeostasis of hope is not applicable to young adults, who have small children.

For one year the son’s hope was maintained by his belief that he would survive or at least have some more years to live. The metaphor of a rolling horizon (Twycross, 1995/1998) is more applicable to the development of the son’s hope than a simple algorithm. From understanding his cancer as a chronic illness to realizing that it was a fatal disease was a process of adjusting hope to a progressively shorter life. He was motivated to live and he continued to hope for some time that a new type of chemotherapy would prolong his life. The sorrow that his life would not become what he had planned for was by no means overcome by the value of the things he could still enjoy. In his case, a formula for hope must be expanded. Belief in treatment ought to be taken into
account as a base for hope for survival that in turn might increase his quality of life. If however an increase in quality of life must include realistic desires (Tengland, 2006a) the son’s disavowal did not increase his quality of life.

In the hospital setting the mother did not ask for a private talk with her son’s physicians. The reasons are several, shortage of time being one of them. The hospital staff, the physicians included, seemed to the mother to have a heavy workload, and of course her son’s and other patients’ needs should be prioritized before her own need to talk. Another reason was that it would have felt like treachery to talk to her son’s surgeon about her son’s illness as terminal, as the surgeon and the rest of the hospital staff did their utmost to save his life. Especially when an adult child is seriously ill the communication between the parents, the doctors and other caregivers is difficult (Dean et al., 2005). On the one hand the adult child is in charge of his life and death, on the other a parent is always a parent. It might also be a dilemma for hospital carers whether to talk to parents about the patient’s condition when the child is an adult. This question is also raised in a study on prehospital emergency care (Sandman & Nordmark, 2006).

In modern life a growing capacity to treat devastating illness is contradictory to our increasing discomfort with death.

Breath-taking advances in medical and biological science such as genetics, genomics, proteomics, and in new technologies, such as nanotechnology and regeneration technology, raise expectation for further extending human lives and unrealistic hopes for physical immortality bolstered by a flourishing anti-aging industry. (Wass, 2004, pp. 291–292.)

“Death is often perceived as a failure of medical care” (Singer & Bowman, 2002, p. 4). The mother had the greatest confidence that every cure possible was tried to save her son’s life. Yet it was a great problem to her that the possibility that her son would die was not spelled out. On the other hand the surgeon perhaps consciously wanted to maintain the son’s and his wife’s hope for as long as possible.

Some studies claim that most terminally ill patients want as much information as possible, good or bad (Fallowfield, Jenkins & Beveridge, 2002). On the other hand only 26 percent of the physicians in a European study (Fallowfield, Jenkins & Beveridge, 2002) thought their patients wanted to know about their terminal illness. Even if there is increasing evidence in advanced industrial
societies “that doctors have shifted from a policy of ‘withholding’ to a policy of ‘revealing’ to the patient his or her terminal prognosis” (Field & Copp, 1999, p. 459), Lutfey and Maynard (1998) noticed in a study on communication of bad news, that although the doctor acknowledged to the researcher that his patients were dying, he did not tell the patients straightforwardly. Expressions as “going home, hospice, not continuing chemotherapy, relieving pain” were used to indicate the step from cure to palliative care (ibid., p. 339). The surgeon in our case used the expression “we have to catch him”. The mother interpreted it as synonymous to dying. Despite this yet a second operation was performed and a more chemotherapy was planned. In a study on interactions between family members and staff in intensive care units the issue of implicit and explicit information between staff and the patients’ family members is discussed, claiming that if there is no open communication “family members felt rejected and even insulted” (Söderström, Saveman & Benzein 2006, p. 714). The mother did not feel rejected or insulted, just confused.

To the four types of awareness context, described by Glaser and Strauss in mid 1960, Scale et al. (2006) add full open awareness and Field and Copp (1999) the concept of conditional awareness. Conditional closure is based upon “recognizing the rights of patients to full information and open awareness while acknowledging that not all patients will want this” (Field & Copp, 1999, p. 466). According to WHO the dying patient is entitled to have full information on the illness, as mentioned above. The patient has a right to know that he is dying. On the other hand the patient’s wish to be informed should be taken into consideration when he receives information about his condition (Council of Europe, 2003), implying that the patient also has a right not to know, if he communicates that he does not want to (Mahoney, 2004; Twycross, 1995/1998). The main point is that the patient’s choice to have information should decide what information is given—not the discomfort that delivering bad news might imply to the caregivers (Field & Copp, 1999). The patients’ right to have adequate information should be prioritized (Blasszauer & Palfi, 2005), taking their own awareness into consideration irrespective of the stress it might give rise to in the caregivers.

The son left the hospital some weeks before he died with a box of chemotherapeutics, signalling that he was under treatment. Perhaps he would need to be medicated for the rest of his life, he was told, as his illness was, according to the oncologist, chronic. Like the patients in a study by Copp (in Field & Copp, 1999) the mother experienced that her son controlled his level of awareness in a way that was tolerable for him. His understanding of the rest of his life was
to begin with some years, but it became progressively shorter. The communication gap between the mother and the son widened as the son slowly deteriorated before his mother’s eyes. Some weeks after second surgery, he, together with his family, insisted that he should be cared for at home. Still the mother and son did not talk about death.

**Phase 4: Shared sorrow**
In phase four the palliative home care team was introduced into the care of the son. The mother, as the only one in the family, also interpreted the arrangement as yet another sign that her son was dying.

As mentioned, the delivery of bad news about cancer is an ongoing communication process (Brixey, 2004). The importance of wordings, situational settings and the judgement of the patient’s and the family members’ capacity to receive the information are crucial not only in palliative care, but in all situations where confronting, often devastating news, is to be broken (Bruce & Schultz, 2002). In a family setting each family member must be assessed according to the need and ability to cope with the information. One of the ways in which guidance and support should be offered to individual caregivers is to allocate time to talk about their needs (Hudson, Aranda & McMurray, 2002). Not only time but also timing is important (Hudson, 2004; Hudson, Aranda & McMurray, 2002).

The concept of control, embedded in autonomy, can be included in the understanding of the son’s hope and disavowal. Personal control is a core concept in oncologic nursing practice. Some early studies on control indicate that most patients want control over treatment decisions, whereas other studies report that a majority allows their physicians to control treatment decisions. As length of time since diagnosis increases the patients attribute control over their health to external sources. (Volker, Kahn & Penticuff, 2004.) The son reluctantly realized that his scope of control decreased during his palliative care, though it was greater at home than at the hospital. Finally, his journey to acceptance was completed, even if reluctantly, according to the mother’s experience. In his “turning the corner” (Volker, Kahn & Penticuff, 2004), that is when he stopped his treatment, he still searched for control over his dying process. He declared that under no circumstances would he accept sedation to the extent that he was turned into a “vegetable”. Like the non-believers in a study by Toscani et al. (2003) he wanted to stay fully aware and safeguarded his identity right to the end. The palliative team respected his integrity and maintained his control as end-of-life experiences. The team involved him in his treatment,
gave him information and time to adapt to it, and ensured him to be pain relieved. The team also made him believe that he could die in his home. In his last days, vulnerable as he was, he was never powerless (Proot et al., 2003). “Vulnerability does not mean powerlessness” (Proot et al., 2003, p. 120). Greater experience of control can be associated with a better quality of life, low self-reported anxiety, and greater purpose in life. If quality of life is measured by the extent of experienced control over life, there was some quality in the son’s life during his last week and the palliative home care team’s contribution was substantial.

When the son was convinced by support and direction from the palliative team that neither his fighting spirit nor chemotherapy would have any impact on his cancer, he chose to avoid the side effects of the treatment.

The best end-of-life decisions are made in a reflective process where the individual has to consult with medical personnel as well as with other family members. (Doka, 2005, p. 87.)

The son seemed to discover his “own answer” (Byock, 1996 in Hayes, 2004, p. 43), even if he asked his wife and mother to take part in the decision-making talks to the palliative team, thus giving them opportunities to make an input to his decision. It is valuable to involve family members in end-of-life decisions (Doka, 2005; Seale, 2006). According to the mother’s experiences, the son was not rushed into a decision, but made up his mind in a “deliberative process” (Doka, 2005, p. 89). Instead of using his decreasing energy to fight his cancer, he accepted that he was dying and used his last week to arrange for his wife’s and daughter’s future lives. For the short time he had left his hope was directed toward those he cared for and their future. To look forward and to try to arrange the life of loved ones are not uncommon among dying patients (Miettinen, Alaviuhkola & Pietila, 2001). The mother could support him in doing so and the communication between the son and the mother was again warm, open and honest. The mother experienced her son’s death as peaceful, albeit his trajectory to death was devastating.

The concept of dying with acceptance is based upon weak methodological foundations and strong social expectations (Hart, Sainsbury & Short, 1998). The overall problem of doing research on dying has been discussed in a previous section. It might be questioned if theories on death and dying intending to explain the experiences of death are theories at all. In a Popperian way they are not, as they can not be falsified. According to Popper a theory is a state-
ment that can be falsified. We will not ever know how a dead person perceived death. Those who are present when a relative, a friend or a patient dies are those who can provide information on the last step of the dying process. Depending on their relation to the dying the observers might have different ways of experiencing and describing the death. To experience a loved son’s death as peaceful is more comforting than perceiving his death as agonized. The “good death” has become the trade mark of palliative care, and there is also a risk that the lives of dying patients are shaped by caregivers to fit the hospice philosophy and expectations of what makes a “good death”. There might be tensions between caregivers enabling patient choice on the one hand and on shaping the lives of dying people to the prevailing ideal on the other (Hart, Sainsbury & Short, 1998).

The Western contemporary “general medical culture which values patient-centred practice” (Seale et al., 2006, p. 2870) in favour of a paternalistic one seemed to the mother to have underpinned the communication between the son and the palliative home care team in the son’s decision to stop his treatment. Retrospectively there is however no way of knowing for sure what made the son come to his decision. As Kellehear in Hart, Sainsbury and Short, (1998, p. 71) claims, “the good death”

...is ‘good’ in two senses: it is good at the individual level in a psychological sense as it gives the dying person opportunities for order and control, and it is ‘good’ at the social level as it provides a series of rites for appropriate disengagement and the exercise of professional power and expertise, and thereby the creation of private profit.

The son was thus a “good patient”. “Good patients are cooperative and compliant, and nurses feel frustration when a patient deviates from the dying trajectory, which is based almost entirely upon the particular disease of the patient” (Hart, Sainsbury & Short, 1998, p. 72). Whether the choice and control lay with the son alone or his decision to stop treatment was founded in a negotiation process between himself and those involved in his care, his wife and his mother included, is not possible to know. Most likely the son was influenced by the information from the palliative team and the mother would like to think that he made his own informed decision.

Some of the elements in “good” and “bad” deaths appear to be shared across many cultures (Seale & van der Geest, 2004). Bad deaths are connected to violence, suicide, unexpected death in childbirth, a death away from home,
when the body cannot be returned for burial, and the like. A death before one’s
time is regarded as particularly “bad” (Seale, 2004, p. 973). The son was a
young adult and his trajectory to death and death in itself was “bad”, despite
him having a loving family at hand, a wide circle of friends saying goodbye and
on the whole excellent medical and nursing care, all the elements of a death
“made good” (Seale, 2004, p. 973). Other elements appear to be less wide-
spread, and “the most telling differences in the views about dying occur not
between cultures but within cultures, due to e.g. religious convictions” (Seale

The hospice ideal of the “good death” can threaten “the maintenance of the
organization’s vested interest of cost effectiveness, administrative imperatives,
and the routinization of care” (Hart, Sainsbury & Short, 1998, p. 70). The
modern hospice movement provides for alternative places, e.g. the patient’s
home, and experiences of dying and death, and an alternative philosophy that
is often contrasted with curative medicine. Hospice care provides palliation
with an emphasis on the quality of life, seeking to meet the differing physical,
emotional and social needs of patients on a holistic basis. Some concerns have
been raised both in the academic literature and within the practice domains of
hospice care, that hospice care is becoming increasingly institutionalized and
bureaucratized. If so there is a risk of “a significant compromise in the move-
ment’s guiding ideology” (Hart, Sainsbury & Short, 1998, pp. 69–70).

“There is some evidence that open communication is helpful to carers”
(Pitceathly & Maguire, 2003, p. 1520). Talking to the nurses about her fear
and despair concerning her son’s death were not a means for the mother to
grieve in advance; rather she wanted to prepare herself. Efforts that have been
made “to describe a subject’s mental state prior to an expected death of a loved
one have proved to be elusive for scholars and investigators alike” (Fulton,
2003, p. 343). To the mother it was not a matter of grieving her son’s death
anticipatorily, but to seriously prepare herself for it. In fact she did not think
very much about her own grief during her son’s terminal illness. She was how-
ever anxious about the moment of death. The assumption that grief work
could be accomplished prior to death, that anticipatory grief is possible, never
occurred to her. Instead the mother thought that when her son was dead she
could deal with her own grief and that nothing could be worse than seeing her
son’s despair and sorrow.
To grieve anticipatorily would have been as if there is a certain amount of grief work to be done, that can start even before the loss (Fulton, 2003). The assumption of anticipatory grief also implies that grief is linear (Fulton, 2003), a model that does not fit into the model of grief applied to the mother in this study. (See the chapter on reconciliation.) When used, preparatory grief is defined as “the total set of cognitive, affective, cultural and social reactions to expected death felt by the patient and family” (Mystakidou et al., 2005, p. 834). It might be put under question whether the concept of preparatory grief must be used to discuss hope at the end of life, as is suggested by Mystakidou et al. (2005, p. 839). It seems more adequate to save the concept of grief to a person’s reaction to loss by death of a loved one.

It was a great relief to the mother to talk to the nurses in the palliative home care team about her fear and despair. She felt recognized by the nurses and the physician. The mother was no longer a hidden patient. Her feelings of guilt and betrayal for not sharing her son’s hope were handled with compassion. Besides, the palliative team taught her about her son’s disavowal as a coping strategy and as a source for hope. Intellectually it was hard for her to understand why her son, a scientist, was still hoping to survive for a fairly long time, when science in fact ought to have told him otherwise. Her realization of the son’s impending death was acknowledged and thus could be talked about, before her son had accepted the seriousness of his illness. She had the possibility to openly ask questions about what was on her mind but was almost forbidden to think about, not to say talk about: her son’s moment of death. She could of course not be comforted, but the team helped her feel less confused. The team urged the mother to do all the small things to comfort her son as best as she ever could, thus empowering her to be an important caregiver. This points to a need for each family member to be met individually, which in turn demands flexibility from the palliative team to be able to tailor the support (Perreault & Fothergill-Bourbonnais, 2004).

In a study based on in-depth interviews with nurses to dying children “hope was considered the central element that helped families through the experience of childhood cancer. … the health professionals believed they had an important role in fostering hope” (de Graves & Aranda, 2005, p. 138). This finding is contradictory to the mother’s experiences in two respects. First, in the referred study hope is related to the family as a unit. To the mother it was of importance that the nurses talked to the individual family members, according to their individual needs. Secondly, it might be questioned whether a trustful relation would have been established between herself and the nurses had they
tried to implant hope into her. The level and progress of awareness of an impending death has been shown to differ between patients and relatives (Hinton, 1999). “The individual evidence, ... clearly contradicted simplified theories that everyone steadily advances through stages to full acceptance” (Hinton, 1999, p. 32).

**Summing up**

To the mother it was of crucial importance that the palliative team recognized, acknowledged and respected her as an individual and did not try to maintain hope in her that she did not have, but empowered her to contribute to make her son’s life as good as possible during his last days. It was also important to the mother that the team respected the son’s hope as long as it did not jeopardized his life or his quality of life negatively. The mother’s experiences of the communicative support could be characterized by the broad concept of *empathy* to the patient as well as to the other family members.
COMMUNICATION IN ACTION BETWEEN FAMILY CAREGIVERS AND A PALLIATIVE HOME CARE TEAM

Introduction

The mother’s experiences of the verbal as well as nonverbal communication between the palliative home care team and the family caregivers are described and interpreted in this chapter by the mother. The mother appoints herself a spokesman for the rest of the family.

Many palliative nurses took part in the home care of the son. Some of them became closer to the family than others. One of the nurses had the main responsibility for the care. A physician was included in the team.

Everyday family life in the home where death was impending was maintained to its utmost limit and was encouraged by the nurses. The nurses non-intrusively and self-evidently made themselves at home respecting and encouraging everyday family life. A wide range of services were arranged for the son, e.g. transportations to the university hospital, medicine, a short term bed at a ward, specialists in different medical areas and finally the last transportation of his body from his home to the mortuary. In Figure 6 the professional network as experienced by the mother is illustrated.
A key concept in the interpretation of the communication during the son’s palliative home care is trust between the son and his family on the one hand and the palliative home care team on the other. Trust seems to be a base for the empowerment of the family members. The main factors, besides the nurses’ medical professionalism influencing trust were accessibility, flexibility and continuity.

**A narrative on communication in action**

*The introduction to palliative home care*

When my son had spent almost a month at the hospital clinic and still needed antibiotics each eight hours he desperately wanted to go home. A palliative home care team agreed to help him daytime, and came to his home to give him the antibiotic infusions. For treatment at night he had to go to the university hospital. For some weeks he and I went to the hospital each evening at nine o’clock to spend the nights there.

Nurse N, who had the main responsibility for my son, and Dr P, the physician connected to the palliative home care team, visited my son at home to introduce themselves and to get to know him and his family.

Dr P asked us to buy a shoehorn for him to use when he came to visit his patient.
By this request Dr P showed that he would come often to the family, and that he respected the “rules of the home”. Furthermore, taking off your shoes when entering a home in Sweden is an act of familiarizing.

The nurse asked for a place in the bathroom to put the equipment box, a big black carrier, that was locked. It got its own place in the bathroom upstairs, beside my son’s bedroom.

The “black box” became a piece of furniture in the home. It was there to stay for some time, indicating that the nurses would be there on and off and have a base in the home. In a way the nurses were present even if they physically were not in the home, the box was like “a safety box”, assuring the family that help was available if needed.

Nurse N brought a green shoe-box-sized box to my granddaughter, with her name written on it in capital letters. The box contained gauze bandage, plasters, injection equipment (no needles of course), tubes, compresses, surgical tape, and other medical things, not harmful for a three-year-old child, and useful when toy bears and dolls were taken ill and needed care.

The “toy box” communicated that the palliative home care team involved also the young daughter, my granddaughter, in the care. She learnt to know the nurses who came to care for her father. The nurses and the physician became persons, who could do good things for her father. The nurses and the physician wore informal clothing. The little girl learnt to be aware of the tube to the infusion when she hugged her father, that her father sometimes was too tired to play, that she had to be calm in the bed, when she and her father watched video tapes together. Of course she also used the equipment in her box to care for her father, and the box was frequently refilled by nurse N. The daughter was in a way a member of the expanded team, caring for her father.

The palliative care expands

After some weeks my son was formally cared for by the palliative home care team, i.e. he was no longer a patient at the university hospital where he had had surgery. This implied that the palliative home care team was available for him days and nights. The need for infusions of blood, nutritious liquids and pain relievers escalated and routines were established. The nurses from the team successively became a necessary and substantial part of the family life.

In a very self-evident way the nurses asked for a place in the fridge and a
cupboard in the kitchen where they could store the medicine. They made themselves at home.

The way in which the palliative home care team made the home their working place was never regarded as an intrusion. Instead the nurses communicated that the home was a place for caring and nursing as well as for family life. The nurses never went into the rooms that were “private”, e.g. the office and the guest room, nor did they go into the daughter’s room, if not invited.

The kitchen was a place for talks. As the infusions, given at least twice a day in the beginning and more often as the illness proceeded, took about an hour, there was time for talk. In the kitchen over a cup of coffee, we all had the opportunity to ask questions in private, articulate our fear, be acknowledged and comforted. There were times and opportunities for tears and hugs.

The private often recurring talks in the kitchen, not limited in time, were a relief to me. During the conversations I also learnt how I could contribute to the care of my son. The moments around the kitchen table may also be seen as time for minor evaluations of the care. In our case the daily contact between the nurses and the family caregivers invited my son and the family members to feed their concerns into the care. The “small talks” contributed to an atmosphere of trust.

When my son’s pain was escalating and the analgesic pump was not enough the nurses taught me and my daughter-in-law how to use an injection pen containing additive doses. In complete trust the nurses placed pain-relieving ampoules in the kitchen cupboard. Even if the team came on request it could take some twenty minutes before they arrived. Those twenty minutes would have been very long for my son had it not been possible for us to reduce his pain.

We were encouraged by the team to maintain family life as much as possible.

Even if my son could not digest any food he was told that he could sit by the dinner table. His wife cooked his favourite meals and he sat by the table together with the rest of the family. Even if he just took some food into his mouth, smelled it, tasted it, and then put it back on his dinner plate, there still was a family dinner the day before he died.
Other aspects of family life were also acknowledged by the palliative team.

My son’s favourite position, besides lying in bed, was to sit on the floor on his knees. This position made his ankles sore. No flesh cushioned the pressure. As he became ever more bed bound there was a risk that he would have sores on other parts of his body. To prevent this a physiotherapist and an occupational therapist were consulted. One of the results of their home visit was that a special thick mattress was installed in his bed. This mattress, however, made his side of the bed twenty centimetres higher than his wife’s. It became almost impossible for them to lie down beside each other. I saw this, but thought that it was an obstacle to overcome. My son and daughter-in-law felt very miserable as the value of spending some time physically close was of great importance for both of them. The nurses observed the dilemma. After some thoughts, they managed to “rebuild” the new mattress so both sides of the bed had the same level.

This act of understanding was highly appreciated. My son and his wife were recognized as a couple by the palliative team in a way that I had not. I was focused on my son. The specialist nurses, having a profound experience of palliative care, communicated that they cared for the whole patient and his wife, emotionally and physically, whereas the physio- and occupational therapists, both professionally trained but younger than the nurses, focused on the physical needs of the patient.

The multidisciplinary network
The team was like a shield surrounding the family in our contacts with different organisations and institutions.

The nurses had prepared the pharmacy prior to my visit there. It was arranged for me to pick up all the things at the back entrance of the pharmacy, where I could bring my car. And for sure it was needed. The big boxes containing nutrition and infusion for a week were heavy. I did not have to explain anything. The nurses had prepared it all.

Normally you have to queue at a Swedish pharmacy and the time spent waiting can often be long.

In Sweden elderly persons and persons with special needs can apply for and get almost free transportation by taxi, even a bed-taxi. However, as the travels are coordinated and several people often share the transportation, the time spent
waiting can be considerable. Through the palliative team transportation to and from the university hospital was arranged without the family members’ involvement.

When my son needed a second nefrostomi at the X-ray department at a university hospital everything was arranged by the palliative team. The structures through which the access was given to him worked very well most of the time.

A bed was available at the oncology clinic, where my son could rest after the nefrostomi was in place. Dr P visited my son at the ward to see that he was all right. After a couple of hours he could leave the ward by ambulance transportation.

Contacts between my son and his general surgeon, eye specialist, oncology specialist, nutritionist—a wide range of medical specialists—were established through Dr P. The family members did not have to wait for telephone contact times. Dr P was like “a spider in a net”, and facilitated the access to medical expertise. After a year of illness, my son and his wife were relieved from the struggle of contacting hospitals for information and appointments.

The end of the palliative care

On the day when my son died the team was called upon at two o’clock in the morning. I was asleep and my daughter-in-law phoned the team. The nutrition infusion was taken away.

At five o’clock in the morning his wife cried out:
“Now you have to come”.

I noticed that the infusion was taken away and realized that death was close.

The nurses were called upon again and came immediately. They helped to change the bedclothes, found the most comfortable position for my son, wet his lips, and checked on the analgesics. At this time my son was still conscious but had difficulties talking.

One of the nurses stayed by my son. His brother was already there as he had spent some days together with the family, taking part in the care of his brother. His sister and father were called upon.

The presence of the nurse was a relief to me.

Some close friends came to say good bye. In the afternoon my daughter-in-law, my son’s father, sister and brother, and I were gathered around my son’s bed, holding his hands, massaging his feet, touching him but foremost talking to him. I said to my son that he had done everything that was in his
power to live and that he could do no more. I tried to tell him that what he had given to his daughter would have a major impact on the rest of her life. She would always carry all the love she had received as a safeguard to be used when needed. I told him that the family would do everything to help each other cope when he was no longer there.

At some point, when my words were hindered by tears, the nurse said:

“He hears what you say.”

I continued to talk about all the things he had given all of us and that he could be assured that his daughter would be supported in every possible way. Everybody would do their utmost to carry on. His wife repeatedly told him that she loved him, kissed and hugged him.

The nurse left the family in the afternoon leaving my son surrounded by his family. I was beforehand prepared for the moment of death. The nurses had explained to me what would or might happen physiologically. I was not afraid of the moment of death. I did not mind that the nurse left the family.

In the evening my son’s mother-in-law played with his daughter in the room next to his bedroom. Soft noise from their playing was heard through the opened door. At seven o’clock, her ordinary bedtime, her mother told her:

“Now you have to say a very very nice good-night to daddy. Daddy is dying and he will not be there when you wake up in the morning.”

The daughter did as she was told.

Some ten minutes later my son died.

We immediately phoned the team, telling that my son was dead. As fast as possible two nurses came to the home, nurse N being one of them.

The nurses made the examinations that are legally required to declare death. Then they and the family all gathered in the kitchen. There was time to talk about the last hours, there were opportunities to weep, to share hugs. The nurses said they would help out dressing my son and arrange for the rest of the family to say good bye. His wife chose his clothes and ironed his shirt. One of the nurses and my son’s younger brother arranged my son in his bed and lit a candle in the window.

The nurses took charge of the practicalities. They arranged for the last transportation. And they stayed as long as the family members wanted them to. There was an atmosphere of respectful silence in the house. A cloud of sorrow surrounded the family.
Interpretation

*Flexibility*

There is a profound need to address variety in cultures, both globally speaking and as contexts within cultures, in order to deliver a good palliative care (Singer & Bowman, 2002). Variety must be dealt with partly on a structural level but even on an individual level cultural aspects of values and behaviour are regarded as key variables in palliative care, along with life experiences, socio-economic status, and personality differences among patients and family caregivers (Mystiakidou et al., 2002b).

On an institutional level effective communication and smooth cooperation between a wide range of institutions, e.g. different hospitals, different departments within hospitals, on one hand, and the palliative home care team on the other, facilitated the home care of the son. The son received palliative care as well as medical curative treatment, i.e. chemotherapy, at the same time. One reason might be that there are few absolutes in health care (Hayes, 2004), implying that “cure and palliation are not mutually exclusive categories” (Meghani, 2004, p. 152). Another reason was that the physicians involved in the decision on the palliative home care realized that it would benefit the son specifically but also his family if he spent as much time as possible at home, irrespective of whether he was dying or still under curative treatment. The different institutions made pragmatic use of the rules of the system, saying that one department should have the main responsibility for the care of a single patient, i.e. they overlooked the system rules to the benefit of the patient by sharing the formal responsibility for the son.

The medical resources available to the patient are fundamental in palliative care (Mirando, Davies & Lipp, 2005; Watters et al., 2005). The importance of making rapid changes that is a crucial component in palliative care (Brokel & Hoffamn, 2005) was facilitated by the established network between different organisations and institutions connected to the son’s palliative care. The importance of multidisciplinary support in palliative care is acknowledged (Burns et al., 2004).

The development of digital telephony during the last decades has made personal contact with many of the social institutions in Sweden, such as hospitals, general practitioners, primary community care, social workers etc. very difficult. Many institutions have telephone hours and answering machines. In the palliative home care where most needs were urgent, the immediate access to the palliative home care team was of utmost importance to the family.
Around the clock there was a real, familiar person to talk to on the phone. As most of the caregivers, in a study on medication management of symptoms in patients with cancer near death (Kazanowski, 2005), the family called the palliative team to report on the son’s symptoms.

The channels of communication between the palliative home care team and other care providers that is most important for terminally ill patients, seemed to be prerequisites to make the care multiprofessional and interdisciplinary (Brokel & Hoffman, 2005; Miettinen, Alaviuhkola & Pietila, 2001; Mirando, Davies & Lipp, 2005; Powis et al., 2004).

For each terminally ill patient and each family the palliative home care team’s actions should be adjusted to when, where and what, i.e. the context in which the care is carried out. The need for flexibility is obvious (Singer & Bowman, 2002). The palliative home care team should be able to assess not only the patient’s needs but also the family members’ capacity and let them take an active part in the palliative care. This calls for communication (Brazil et al., 2005a). It is not common that the whole family is invited for conversations (Benzein, Johansson & Saveman, 2004). The narrative exemplifies the nurses’ ways of communicating, verbally and non-verbally, with the family members. The mother had opportunities to talk beforehand about her son’s moment of death. The patient and his wife were recognized as a married couple, communicated by the means of the rebuilt mattress. Their daughter was involved in the care and “equipped” to do so. The equipment box given to the three-year-old daughter in the family communicated to her and to the family that she was considered an important person in her father’s care. Even if research on infants’ and toddlers’ responses to death is sparse, there seems to be an agreement that the youngest family members should be advocated and included when appropriate in family caring activities (Hames, 2003). The narrative illustrates the nurses’ flexibility and creativity that “allowed for the patient’s individuality to be valued and respected” (Brajtman, 2005, p. 77) as well as the family caregivers’.

The nurses urged the family to live as normal an everyday life as possible. Family habits, exemplified by evening meals, even if not times for celebration (Forbes & Rosdahl, 2003), were encouraged by the palliative team, based in their knowledge of the particular family. The meaning of food is often an issue in narratives on dying. These stories can “be understood as a form of resurrec-tive practice, serving to establish the adequacy and justified pride of the speaker in having fulfilled the obligations of social bonds up to the last
moment of life” (Seale, 2000, p. 39). This may be the case also in the mother’s writings, even if the writings more indicate a desperate effort to maintain family habits. In a study of terminally ill patients’ family members, living a normal family life was considered one of the elements in palliative care that “brought happiness, brightness and joy into the patient’s life” (Miettinen, Alaviuhkola & Pietila, 2001, p. 267). However, happiness, brightness and joy are not words to describe the atmosphere in the son’s home.

The act of respectful care for the son and for the family when the son was dead is a further example on communication, taking the whole family into consideration, and still regarding each of its members as individuals.

Continuity

The flexible way of arranging a combination of care from the palliative home care team as well as cure/care at a hospital ward contributed to the continuity in the overall care. The organisation within the palliative care also promoted continuity. A restricted number of nurses were key persons in the home care. It is not in the scope of this study to discuss the internal communication within the team. However, it must be mentioned that the family caregivers realized, that the communication within the team must have been considerable. The problem of interdisciplinary communication (Street & Blackford, 2001) was never an issue for the family. The nurses who came to the home were informed by the other team members about the latest news as well as from medical specialists outside the team. It was not up to the family members to build bridges between the professional caregivers.

The impact of frequency and continuity of the contacts between the nurses and their patients are central in the provision of care to terminally ill patients and their families (Brajtman, 2005; Miettinen, Alaviuhkola & Pietila, 2001). Two different though related components in the care of family palliative caregivers have been recognized to promote continuity; presence and time.

Time is of utmost importance in palliative home care (e.g. Benzein, Johansson & Saveman, 2004; Glimelius et al., 1995; Hudson, 2004; Hudson, Aranda & Mc-Murray, 2002). During the nurses’ daily presence in the family time was given for small talks as well as information. No issue brought up by the family members was of too minor importance for the nurses to listen to. There was time for family members to share feelings with the nurses in the team. Time was enough and informal situations were created where communication could develop. The literature on small talks is inconsistent. Social conversations and
chit-chat might be regarded as blocking more profound topics (Skilbeck & Payne, 2003.) In our case the small talks were perceived as very important and fruitful from the family members’ point of view.

The importance of a patient-centred rapid-cycling feedback can be seen as a means to improve the quality of end-of-life care (Powis et al., 2004). In a way the “small-talks” were also moments of evaluating the care, and thus the patient and the family caregivers could contribute to the necessary changes in a short term perspective. Time was offered to the family caregivers to report on the care they themselves delivered, to ask questions, and to articulate problems they encountered. To the mother the importance of the informational talks could not be overestimated, even if they were not planned in a schedule-like way as in a study by Glimelius et al. (1995). The talks were spontaneous, problem oriented, often individual and on a daily basis. They came naturally when needed and were adjusted to the patient’s and each family caregiver’s needs. Questions that emerged on one occasion could be elaborated on and deepened, as the same nurses visited the patient frequently.

Empowerment of the family members

In the literature on terminal care the concepts of powerlessness and helplessness are often discussed. Problems to establish a clear and useful definition of powerlessness have been encountered (Milberg, Strang & Jakobsson, 2004). One explanation to the difficulties might be that the concept of powerlessness must be divided into powerlessness in curing and powerlessness in caring.

Empowerment of the family members

It seems important to increase understanding of the concepts and, when possible reduce powerlessness and helplessness in the context of palliative care, because next of kin are often a prerequisite for successful palliative home care and fulfilment of the patient’s wish to remain at home despite approaching death. (Milberg, Strang & Jakobsson, 2004, p. 121.)

When a patient is terminally ill everybody is powerless in regard to curing, family caregivers as well as professionals. When it comes to powerlessness in caring, family caregivers who choose to care for the patient at home can be empowered by professionals. In our case both family and professionals were powerless in curing but the family members did not feel powerlessness in caring. On the contrary, their contributions to the care were utmost meaningful to them and the fact that they were encouraged, invited, allowed, and taught how to best participate in the care turned out to be of use in their grief. The palliative team made the family members feel competent and important in
the care and helped them understand and finally accept the professionals’ powerlessness and helplessness in curing. Furthermore, without the palliative home care team it would not have been possible to provide appropriate care for the son at home, and the family caregivers’ experiences of stress, burnout and ill health would most likely have had serious consequences, as they all wanted the son to be cared for at home. “Committing to the person to the end” was the core variable in a study on lay caregivers to terminally ill patients, and the expression very well describes the family members, to whom the son “was still very much a person with whom they related”, even if he was near death (Kazanowski, 2005, p. 180.)

“Universally, we are exhorted to help others” (Doka, 2003–2004, p. 45). Helping a child is not only exhorted—it is biological. To care for the offspring is universal not only to human beings but also to all living species. To take part in her son’s care was self-evident to the mother and not founded in a decision-making process. It would be an exaggeration to claim that the caregiving brought “spiritual gifts to everyday experiences” (Doka, 2003–2004, p. 47). It was naturally carried out when it was needed, to the best of the mother’s knowledge. There was no need for rationales. Rather she was thankful to be invited to participate in it, as she generally was when called upon to help out in her children’s families. It was not the caregiving per se but the reason for it that was a burden for the mother to bear.

To have been able to care for her son during his terminal illness and to meet his wish to die at home contributed in hindsight to the mother’s feeling of having done everything she could as a mother. There were no regrets in relation to the care her son had received. This knowledge was like a platform, from which her reconciliation process could start and it had a positive emotional impact on her, also found by Grbich, Parker and Maddocks (2001) in a study on family caregivers. This is not always the case. In some cases a home death might “greaten the distress of those who live on” (Addington-Hall & Karlsen, 2000, p. 162).

Through the palliative home care team the family members learnt to use their capacities in the care of the patient. Decisions were made in collaboration between the patient, the family caregivers and the palliative home care team, and thus the health care professionals involved the consumers also in the development and evaluation of strategies, as recommended by Hudson, Aranda and McMurray (2002). The pedagogy used to empower the family caregiver can be described as learning in master-apprenticeship situations, that is also
recommended when general practitioners develop and maintain palliative care skills (Mitchell, 2002). The mother and the wife were laymen, when it came to medicine and nursing. They learnt by watching the nurses and by participating in the care, thus being members of the entire team. Such learning is situated, that is it is embedded in practice (Lave & Wenger, 1991) and goes on in interaction between an individual and a culturally constituted collective (Lauvås & Handal, 2001). The nurses relinquished their power and trusted the patient and the family members to formulate problems and to find solutions to them.

This is a central aspect of empowerment (Tengland, 2006b). The nurses were facilitators rather than leaders in the care that was not directly connected to medical treatment. For instance; the wife learnt how to start the infusions and to give the patient medication according to a medicine list written by Dr P. The mother learnt how to change ostomies and how to give the son additional analgesics. Family members to terminally ill patients who are cared for at home often become “the medicine managers”, and the strategies of using “medication boxes” and “written schedules and diaries” (Kazanowski, 2005, p. 177) were used. The family members learnt how to solve some of the emerging problems. They learnt to act and do, but did not always know why their actions worked. They had to rely on the nurses, and after some weeks a mutual trust was established. Not only did the family’s reliance on the team grow, as the care the patient received to their knowledge was adequate and effective, they also felt that the team trusted the family members’ capacity in different respects. The distress among the family caregivers was thus lessened through their involvement in the care. Their problem-solving ability was learnt by the presence of the palliative nurses and their confidence as caregivers increased through gentle guidance. For some time the nurses in the palliative home care team were like secondary family members, urgently needed and acting upon the patient’s and the family members’ needs.

Communication between the family and the professional caregivers was a prerequisite in building a trustful relationship that was also a base for support to the family caregivers. Thus one might claim that communication and support were intertwined in the palliative home care. If the family members do not communicate their needs of support it might be difficult for the professionals to deliver it. On the other hand the family taking part in palliative home care by far most is just a family caring for a loved one, and the family members do not always know how to verbally articulate what they need in the challenging situation. The professionals’ sensitivity is a cornerstone in the communication. The palliative care team’s interaction with the family members was warm and inviting. The family members never felt they were burdens to the nurses, as
is sometimes the case in palliative care carried out by district nurses (Benzein, Johansson & Saveman, 2004.)

**Summing up**
The palliative home care team communicated to the mother that no effort was to be denied in caring for the son. A network of supportive arrangements was made available to the son and his family. The family members were also encouraged to participate in the care and were empowered by the team to do so. Not only did the team recognize the family members’ emotional needs but also their needs to do anything they could for their husband, father, brother, and son. The ability to see and acknowledge the individual family member’s wishes to take part in the care and ability to learn can be discussed in a framework of empathy.
WORDS THAT MADE A DIFFERENCE IN GRIEF AND BEREAVEMENT

Introduction

Some weeks after the loss of her son the mother was in a state of post-traumatic stress, according to her family doctor. The symptoms of her post-traumatic stress can be summed up as feelings of guilt, lack of knowledge, physical breakdown, anxiety, lack of control, obsession and feelings of stigma, all symptoms that are frequently mentioned in the research on parental grief.

The symptoms illustrated by the narratives impaired the mother’s everyday life during her first year of grief. However, the symptoms did not appear one by one. They accumulated during the first six months after her son’s death, each taking more or less space and energy. Sometimes her sleeplessness occupied her most, sometimes her guilt feelings, and sometimes she had difficulties meeting people who were not members of her family or very close friends. Hence, the kind of support she needed varied form time to time.

Information, talking about control, friendship, sharing a laugh and shared experiences were identified as important in the mother’s reconciliation process. The support was predominantly provided by people around her, friends and family. Support from professionals was to some extent customized by herself as she articulated her needs and knew where to find help.

A narrative on words that made a difference in grief and bereavement

The day after my son’s death, October 2003: Guilt

Suddenly I heard nurse F’s words within me:
“He can still hear what you say.”
These words were uttered just before nurse F left my son, dying in his bed surrounded by his family.
During his last hours I kept telling him that we would help each other in the times to come when he was no longer with us. I also told him:
“I know that you have struggled to the end of your strength. You have done everything you ever could to survive. You could not beat your cancer. You must allow yourself to let go.”
What if I said the wrong words? And perhaps my words were wrong. Is it really all right for a mother to tell her son in a way that it is all right for him to die? I asked myself if nurse F’s words had been a warning.
I phoned nurse F who immediately visited me and assured me that I had said the right words.
I felt very relieved and also somewhat silly. In my heart I knew that I said just the right things, but vulnerable as I was, I began to doubt my own judgement.

December 2003: Lack of knowledge
Never during my son’s illness did I have the opportunity to talk to his surgeons in private, nor did I ask for it. When some weeks had passed after my son’s death, I asked for an appointment to see the surgeon. I wanted to understand what physically had happened to my son. Within me I felt that the surgeon, the same age as my son and a father too, was affected emotionally by my son’s illness and the fact that he could not cure him. Still we had not talked about death during the year of my son’s illness.
The surgeon came on time to our meeting, carrying my son’s file. He put the file on the desk between us.
“There is a black cross on his file”, I said.
“Yes”, the surgeon replied, shaking his head and looking sad.
The black cross made me weep and I was not very receptive to his information, even if he gave me time to get answers to the questions I had written down.
My first question was:
“When did you first realize that my son was terminally ill?”
“When he had his first operation I understood that his cancer was extremely serious. But I was not sure his trajectory to death would be so fast”, he answered.
He described my son’s illness and the exponential development of the number of cancer cells that put my son’s cancer beyond control.
I told the surgeon that I had read resignation in his face for a long time.
However, I wondered why he had not talked to me about it during my son’s illness, but I did not ask him. He invited me to come back if I had any more questions. I have not seen him again.

**December 2003: Physical breakdown**

A month after the funeral I was on my way from Stockholm where I had been on business, about to take a break from work and looking forward to spending Christmas together with the family. My plan was to stay for some days with my daughter and together with her and her two children continue to Malmö and my daughter-in-law, my son’s widow and her daughter.

Suddenly on the train my tears began to flow. I heard a voice within me saying:

“You should not have let your son die. A mother does not let her child die.”

I phoned my daughter on my cell phone and she somehow comforted me. My daughter and my two grandchildren met me at the railway station and I felt the joy that grandchildren can give to a grandmother. Their hugs and kisses wiped the tears away.

One evening, when the children were at their daddy’s home, my daughter and I had planned a quiet evening viewing a video tape. I began to freeze. My feet went blue and I had difficulties breathing. My whole body shook. My daughter phoned the hospital and was advised to bring me there. I hardly remember the journey. When we came to the hospital I hyper ventililated and was immediately taken care of by a team of doctors and nurses. I was still shaking.

At a distance I heard my daughter tell the hospital team what had happened to our family during the past months. I was not able to talk.

I stayed at the hospital overnight. The day after the doctor told me to consult my family doctor to discuss with him what happened.

I saw my family doctor, in whom I had great confidence. During my son’s illness he had explained medical matters to me, and given me much more of his time than a general practitioner in the health care system usually does.

We both knew that I had no heart problems, even if I at night felt my heart thumping. He referred me to a heart specialist. I felt guilty using the health care system when it was not necessary from a physical point of view. He reassured me that the examination was OK anyway. When trying to sleep at nights I used the examination result as a mantra:

“You heart is healthy, your heart is healthy.”
February 2004: Lack of control

The social counsellor who was a member of the palliative team that cared for my son at home during his last weeks gave me some words that I could use in my predicament.

“You cannot control what happens randomly.”

My son’s cancer could not be explained by current medical knowledge. He was an athlete at the elite level and exercised regularly, he ate healthy food, he never smoked. His drinking habits were at most moderate. Why he developed such a rapidly growing cancer no one knew. The cancer did not respond to treatment. I knew this cognitively but my emotional state closed my mind to this knowledge. I needed the words from the social counsellor to put me on a cognitive track. When my mind started to catch up with my emotions my guilt feelings slowly—very slowly—started to fade. For a long time my nights started in nightmares, even before I fell asleep.

“What else is out of my control?” I asked myself.

March 2004: Anxiety

The evenings at bed time were the worst time of the day. I was afraid of feeling anxiety, to feel my heart beat irregularly when I lay in my bed. I knew it would take about half-an-hour to fall asleep after I had taken my sleeping pill. These thirty minutes were horrifying. I prepared myself with a paper bag to breath in, if and when I would hyperventilate, I chose some soft music that I liked, I had a cup of calming tea (at least that is what the label on the package said). My rituals were minutely organized. Still I knew, that the anxiety would invade me as soon as I was in bed. Sometimes, for a few minutes I would hope it would disappear—then I phoned a friend. I knew that I could phone her anytime night or day. She had given me some dark chocolate, as she had read in a paper that it was calming.

“Take some chocolate and I will talk to you on the phone till you fall asleep”, she would say.

I put some chocolate in my mouth and we talked till the phone almost fell out of my hand. Not one night, but many nights. After some time the mere knowledge that it was OK to phone her made me feel less anxious.

April 2004: Obsession

One of the reasons for not being able to get off to sleep was that I kept seeing the image of my dead son in his bed. He was like a doll, made of wax. The sight seemed to be there forever.

Even if I had the utmost confidence in the nurses who cared for my son in his last weeks I was not sure that they were right when they told me that the
sight of him would fade away. How could they possibly know? Had they lost a child? In a way I also wanted to keep the sight. It was as if I betrayed my son if I let the sight go away. Was it all right to let it go? Those weeks and months were very confusing. My inner dialogues were chaotic.

My family doctor arranged for me to see a psychologist who specialized in post traumatic stress. It took some time to break the ice in therapy. How could the therapist help me? I asked myself. She did not know me, nor had she met my son. How could she ever understand my loss? Was it a waste of time?

After about five weekly sessions I brought a crucial question to the therapist.

“What can I do to have a reasonably good life now when my son is dead?”

The therapist asked:

“Do you really want me to tell you how to live your life?”

Put so directly the absurdity in my question was evident. We both laughed and the laugh broke the ice. Thereafter we could talk about how to plan the sessions. The therapist told me that she needed time to reflect. We made an agreement that my questions should be dealt with in due order and that in between the sessions the therapist would think about what for the moment worried me and tell me how she could contribute to my thinking the next time we met. Our arrangement worked out very well.

I told the therapist about how the sight of my dead son still tormented me. Her reaction to my question really helped me.

“Do you believe in ghosts?”

“No I don’t.”

“Well then …”

The very clear cut expression from the therapist made me realize how obsessed I was by the sight.

A result from that session was that I went home to look at photos of my son, showing him as a strong, healthy and happy boy, husband and father. Her words were a turning point in my bereavement. The therapist also urged me to use my will power to keep the sight of my dead son away and in this my photo albums were a great help.

Yet another of her expressions made me take a crucial step.

“Grief is a work, and no work should be carried out round the clock.”

She assured me that it was all right to work, enjoy friends, nature, go to a movie, go shopping—to live my life. I had a lot of friends standing by, waiting for me to signal that I was ready to enjoy their company. The therapist told me to use my friends.
April 2004: Stigma

Three months after my son’s death I joined a support group, arranged by the hospital department of palliative care and led by the nurses who had cared for my son at home. I was the only one in the group who had lost a child. All members in the group of five shared the experience of palliative caring at home. Still I felt that our different relationships to those we lost made a substantial difference. I had a need to meet parents who had lost a child and joined a parent bereavement group.

By then I had begun to work on a more regular basis. Thanks to electronic communication I could do much of my work at home. I felt uncomfortable meeting people who were not my friends. I felt very uneasy and sometimes very lonely at work.

Words from a bereaved mother in my support group helped me. She said:

“It was as if I had a stigma on my forehead and as if nobody saw me anymore. They just saw a mother of a dead child.”

Yes, that was exactly how I felt. She put words to my feelings and furthermore she told me how she handled her situation.

Step by step I spent more and more time at work, preparing my closest colleagues by telling them that when I came to work I wanted to work and not to talk about my loss. I did not want to meet people who gave me their condolences. I did not want to hear:

“I know how you feel. I lost my father some time ago.”, because then I rapidly would reply:

“No you do not!”

I felt security among the parents in the bereavement group. We all shared the most horrible experience possible.

Interpretation

Information

Even if grief is said to be individual some general features are recognized (e.g. Attig, 1996; Kagan (Klein), 1998; Sanders, 1992). Denial, disbelief, searching behaviour, i.e. a conscious or unconscious effort to deny the reality of the death of a loved one, is normal behaviours in the first phase of grief. Once the reality of death has been acknowledged deep sighing, anergia, palpitations, fitful sleep, shocking sensations, cognitive changes, (impaired memory and concentration), illusions and misperceptions (seeing, hearing and speaking to the diseased) are normal. In the resolution phase the bereaved is able to part from the possessions of the diseased, talk about the diseased without obvious
distress and no longer avoid reminders of the death and the diseased (Klein & Alexander, 2003).

The mother felt the first symptom of guilt only a day after her son’s death. To come to terms with it she needed information. She knew cognitively that after the death of a first degree relative there are indications that guilt and negative beliefs about the self are highly related to anxiety (Boelen, van den Bout & van den Hout, 2003b). She knew “about the normal reactions to grief” (Clements et al., 2004, p. 150). However, the mother was not capable of using her knowledge. When she posed a very direct question to the nurse in the palliative home care team, who had heard her talking to her son when he was dying, the nurse at once recognized her need for support, visited the mother and assured her that she said just the right words to her son in his last hours. Her answer enabled the mother to suppress her guilt feelings for some time. Of course one can ask what the nurse would have told the mother had she said something that could be considered “wrong”. This, however, did not occur to the mother. The mother trusted the nurse after the son was dead as she did during his care.

At that time the mother did not, surprisingly enough, see herself as a high risk mourner. The nurses in the palliative home care team knew the mother and the rest of the son’s family. The nurses had seen them caring for the son and had talked to them over several weeks. They were skilled palliative nurses and used their professionalism in caring for the mother as a high risk mourner after her son’s death. The nurses in the palliative home care team performed “outreach” (Jordan & Neimeyer, 2003, p. 783), that is they contacted the mother before she knew she would need help in her bereavement. Even before the son was dead a social counsellor affiliated to the palliative home care team was involved with the family.

The mother looked for some answers to understand what happened to her son’s body during his terminal illness, to be assured that there had been nothing anybody could have done to save his life, herself included. She needed to be able to put guilt aside and tried to use cognitive mastery (Wheeler, 2001) as a strategy to address negative cognitions (Boelen, van den Bout & van den Hout, 2003a). The fact that her son was dead was at first incomprehensible and almost surreal.

Some weeks after her son’s death the mother had her first private talk to his surgeon. The communication between him and the mother started in a non constructive way. It was heartbreaking for the mother to see her son’s file
marked with a cross. However, the information from the surgeon helped the mother understand cognitively, that there was nothing medically that could have been done to cure her son. The accumulated knowledge on his type of cancer was insufficient. The mother’s questions on what she could have done were answered by “Nothing” by he surgeon. Still she asked herself for some months now and then: “What if my son had seen another physician?”, “What if we had looked for alternative medicine?”, “What if we had gone abroad to seek help?”

There is a variety of reasons for bereaved parents to have guilt feelings (Sanders, 1992; Singg, 2003): death causation, illness-related, parental role, moral, survival and grief guilt. It is not always possible to relate the mother’s guilt feelings to a specific reason. All the reasons would be applicable to some extent. In the first phase of grief the guilt was probably related to death causation, illness and parental role. Considering that the mother had lost the closest relative possible, a child, her profound negative feelings about herself are understandable. Even if she cognitively knew that she did all she could to help out when her son was ill, did not save herself any effort in the palliative care of him and was acknowledge in her endeavour by the palliative home care team during the home care, she felt guilt for a long time for “letting her son die”. “A mother should not let her son die”, she told herself. She asked herself what else was beyond her control that she did not know of. Her world trembled and she lost her footing. She had a physical breakdown, including anxiety attacks, that can also be aroused through an increased awareness of the finite nature of life (Jones, 1998).

The physician who treated the mother when she broke down physically recommended her to see her family doctor. The mother’s family doctor connected to the primary health care system and in whom the mother had a great trust confirmed the information from the surgeon and further reassured the mother, that she could have done nothing to prevent the development of her son’s cancer. Even if the mother knew this beforehand, she needed the confirmation over and over again. The mother finally had to realize that until science contributes to the knowledge of leiomyosarcoma, there is no answer to the question “Why did my son have cancer?”. The mother could see her son’s illness almost as a random event, as some parents who lost their children in accidents do, and thus feel less guilty (Murphy, Johnson & Lohan, 2003).

The mother’s anxiety was taken seriously. Her family doctor used his professionalism to make her feel less anxious, e.g. by letting her have a heart
examination. She was also prescribed some sleeping pills, some pills to correct her by then high blood pressure and he advised her to see a psychotherapist. Her doctor recognized her as a whole and not as body and soul separately. His professionalism was manifested in a holistic way. She felt comfortable when seeing him, as he had known her for a long time. The combination of teaching her about her son’s cancer, reminding her of the physical consequences of anxiety and especially letting her have a heart examination, based on her psychological needs, gave her different kinds of information and supported her in her struggling with the anxiety. Even if her heart was beating heavily when she was going to sleep, she knew that her heart was all right.

The importance of accessibility and continuity, i.e. that the mother could have an appointment at request to the same doctor during the year of her son’s illness and during her grief process was of great value to her. The fact that her family doctor had known her before her son was ill, and knew her physical status in normal circumstances contributed to the mother’s comfort when seeing him in the specific situation. At the primary care centre the same nurses and her family doctors stood by her. She did not have to repeat information. She was recognized as a patient in need and her problems were taken seriously and dealt with. She was treated respectfully as if her coming to terms with her grief was a mutual issue. In a study of caregivers to patients dying from cancer, Burns et al. (2004) found that general practitioners were identified as sources of information about health and community services for family caregivers, even if most information on community services mainly came from informal sources.

Control
Considering that the mother before her son’s death perceived herself as a good enough mother, professional, and friend, having control over her everyday life, the loss of her son ruined her self-image. She was powerless in relation to her son’s death—in what other situations was she powerless—she asked herself. What other situations were out of her control?

To the social counsellor, connected to the palliative home care team, the mother could talk about what we as a human beings are and what we are not able to control. The counsellor put the mother on track. The sense of intense helplessness when meeting an experience that is out of one’s control seems to be a commonality in parental loss (Dean et al., 2005). The counsellor helped the mother to regain control over life again. The mother had to relearn what she in fact could control, and to be realistic and non-judgemental about herself.
and her power. The social counsellor encouraged the mother to organize her life by planning her days and weeks in a very straightforward manner to include physical training, work, seeing friends and family etc. in a constructive blend. She started to regain an outer control of her life. The counsellor helped the mother to set goals that were challenging enough to motivate her but small enough for her to achieve (Atkinson, 1964). The counsellor’s support inspired the mother to write a list of things that she used to do and enjoyed before her son was dead and that she could control, e.g. listen to music, play the piano, pick mushrooms in the woods, build multivariate models out of data from her research project, make patch work, decorate her home. The mother forced herself to do these things. To her surprise she even felt flow (Csikszentmihályi, 1996) once in a while, that is for several hours she was completely occupied and concentrated and did not think of her son. At first, when she realized that she had enjoyed herself, she felt guilt that can be described as moral guilt (Singg, 2003) and she blamed herself.

When the mother asked the counsellor how long it would take to integrate her grief into her normal life, the counsellor answered that the mother would know when she had accomplished it. The counsellor pointed to her belly and said: “You will feel it here—there will be a place for your sorrow.” At that time the mother was not helped by the words.

*Friendship and sharing a laugh*

The mother’s closest friends had followed her son’s trajectory to death through her. They were continuously updated. Not that the mother had to phone to each of her friends. Her friends developed a communication chain, so that the mother, who was heavily occupied with the care of her son, did not have to spend lots of time on the phone. The arrangement implied that there was always an updated friend to talk to if needed.

A few of the mother’s friends had known her son as a child and adolescent and to these friends the mother could share memories. Whether the mother had a need to talk to others or talking to others was just comforting, a question discussed by Walter and Stroebe (in Walter, 1997) is hard to know. Most likely she had a need, as she talked about her dead son in different contexts, among friends, in therapy, in a parent bereavement group—but foremost within the family. When meeting her friends the mother could just weep, have a hug, a cup of tea, some chocolate, a walk together—do the things friends do when they meet. As her friends knew the mother they also knew her priorities and used them to distract her and give her breaks in her grief. Hence, the most
important context in which the mother was supported, next to the family, was among close friends. The literature on grief and bereavement repeatedly highlights the importance of empathy and presence when asked for (Cutcliffe, 2004; Jordan & Neimeyer, 2003; Murphy & Lohan, 1998). The mere knowledge that her friends stood by was supportive. The impact of good friends could not be overestimated in the tense situation of palliative care. When her son died and her reconciliation process started they had an understanding of what had happened. Continuity in friendship as well as in the care seems to be a profound factor in the reconciliation process.

The mother was advised by her family doctor to see a psychotherapist when she had her breakdown. The information from the psychotherapist on how crises affect human beings was something that she already knew theoretically, but had never experienced and the information helped her analyze her feelings. Not that she could control her sadness, but she could little by little understand her own grief process, and that helped her gain control over her life at large.

During the palliative home care the mother did not realize what feelings the loss would arise in her. She had never before lost a very close young relative or friend. Her physical breakdown surprised her. Not until she had support from a wide range of mostly professionals but also friends was she able to “become honest” with herself, to “broaden the vista” of herself and “the world in which” she lived (Jones, 1998, p. 57). This struggle might be explained in the framework of existentialism, implying an approach that enables a person to become honest with herself (Jones, 1998). To have inner control relates to authenticity, that in turn relates to “self-awareness, self-knowledge and, within confines, self-direction” (Jones, 1998, p. 57). In the discussion of reconciliation the concept of empathy to self will be addressed.

The support the mother received from professionals was perceived by her to be carried out on two levels; a working level of the client and the counsellor and a basic human level (Heid & Parish, 1997). At the second level the psychotherapist showed mutual respect and equality. The empathy shown to the mother was not experienced as simply a mirroring process. Rather it developed into

... a reciprocal process in which therapists take in the client’s experience, interact with it intraphysically, and offer back to the client that experience as it has been touched and deeply understood by the therapists’ essence of being. (Heid & Parish, 1997, p. 61.)
Not until the mother felt coherence, showed in a shared laugh, did she find the psychotherapy supportive. To the mother the therapy developed into a climate “following the client’s agenda” (McLaren, 1998, p. 289) that facilitated the mother's individual process and emphasized the mother rather than following a particular technique. The therapist seemed to find remains of the mother’s inner core to build upon. A core that according to Rogers never totally obliterates how traumatic or negative the environment might be (Green, 2006).

The psychotherapist’s way of supporting the mother might be summed up as “projection hope and hopefulness” (Cutcliffe, 2004, p. 165) into her. Their shared laugh was a turning point, a point that defines before and after (Johansson, 2005), in this case the therapy before and after the shared laugh. “Learning to laugh helps us survive and re-enter life. One of the first signs of depression is the loss of sense of humor” (Gibson, 2004, p. 446). Not until their mutual laugh did the mother find the sessions beneficial. This does not imply that they were not important before, but then the mother did not realize it. Not until a contract was established (Kirschenbaum & Jourdan, 2005), i.e. a mutual understanding of how they were to work together, did the mother experience the therapy as effective.

In the mother’s community post traumatic therapy provided for by the welfare system is limited to 15 sessions. This limitation is questionable, as grief and bereavement are individual and trust is built on the relation between individuals. The time needed in therapy for a bereaved parent varies “from one to two-and-a-half-hours, weekly, fortnightly, monthly, for as long as they need …, which may be weeks, months, or years” (McLaren, 1998, p. 278). Perhaps the mother would not have continued the therapy had she known beforehand that a limited number of sessions were at her disposal. In fact she only used 13 sessions.

In the cognitive process of bereavement individual differences in coping styles and situational factors are determinants of coping with bereavement, indicating that if a bereaved person uses a coping strategy to suppress painful memories and distract oneself it may do little good to encourage the person not to suppress (Stroebe, 1992–1993). The mother’s therapist encouraged the mother not to suppress painful memories totally, but to allow herself to take breaks from them.

Support cannot cure grief (Johnson, 2004). Reviews and meta-analyses of bereavement intervention studies have suggested that bereavement support may
be surprisingly ineffective to mourners at large (Jordan & Neimeyer, 2003; Neimeyer, 2000). Studies show the greatest efficacy of interventions when bereft persons sought help for self-identified bereavement-related distress (Jordan & Neimeyer, 2003). The mother sought help for bereavement distress and she also received different kinds of support from a wide range of sources. To her the support was effective, even if it is sometimes hard to relate a specific kind of support to a specific outcome.

Cognitive therapy, for instance, may be an important component of the treatment of high risk mourners (Boelen, van den Bout & van den Hout, 2003b) and an effective support in instrumental grief, i.e. “problem-solving ways of dealing with loss”, so-called masculine grief. Feminine grief is described as more intuitive (Falk & Lönnroth, 1999; Versalle & McDowell, 2004–2005). Bereaved women also tend to show greater anxiety and difficulties in functioning (Rubin, 1993). Even if there is some overlap between gender, the difference in baseline distress as well as in treatment response seems consistent (Murphy, 2000; Versalle & McDowell, 2004–2005).

The similarities in counselling and teaching are obvious. Only the learner can learn as only the griever can come to terms with grief. The human qualities and the trust building ability that is necessary in counselling and therapy are also needed in teaching. As in bereavement, where the high risk group is more dependent on support, the high risk group of students is more dependent on professional and empathic teaching. The mutual understanding that is for example manifested in a shared laugh is a prerequisite also for the establishment of a fruitful learning environment. The saying that teaching is parasitic on learning might be translated to the counselling area into: Grief and bereavement counselling is parasitic on the clients coming to terms with their grief. And the most powerful tools in counselling are the counsellors themselves (Cutcliffe, 2004) as the teachers themselves are in teaching. Human qualities and ways of being, implicit hope, and ability to create a nurturing, hope inspiring and helping environment are shown to be rudimentary in counselling (Cutcliffe, 2004; McLaren, 1998) as they are in teaching (Holmberg, 1983).

Shared experiences
The mother’s first opportunity to share her experience of palliative home care with persons outside her family group of caregivers was about three months after her loss. The palliative home care team invited former family caregivers to join a bereavement group. In the group the survivors were educated on “the
normal reactions to grief” (Clements et al., 2004, p. 150) and the grieving process. The mother was not able to integrate the information at that time, perhaps because there is no normal grief process. Even if there were possibilities to share experiences of palliative home care, the mother felt that she could not share her experiences from the loss of a child in the group. What helped the mother the most in the bereavement group, was that she met the nurses, who had cared for and learnt to know her son. She assumed they somehow shared her loss.

Bereaved parents are often recommended to join bereavement groups (Gibson, 2004; Murphy, Johnson & Lohan, 2003). The context of giving as well as receiving support in a bereavement group might be one reason for the effects (Wheeler, 2001). Especially for high risk mourners group support may be effective (Dunne, 2004). Homogenous groups, so called mutual groups, are most beneficial to facilitate identification among group members (Davies, 2004; Dean et al., 2005; Jordan & Neimeyer, 2003) and the “most predominant form of supplemental support following the death of a loved one” (Murphy & Lohan, 1998, p. 1). In a study on parental alienation syndrome Baker (2006) stresses the importance of sharing experiences through stories. The benefit is summarized in six E’s: engagement, empowerment, education, enhancement, encouragement and enlightenment. To the mother, the parent bereavement group contributed to these six E’s, not by reading true or fictional accounts but by the parents telling their own stories of grief and bereavement. The shared experiences in the group made the parents’ words credible to the mother, and the mother felt at home in the group. The group was an in-group in a very profound sense, where the parents could without hesitation talk about death and without being afraid awakening fear in each other. It was more essential to the mother to share the loss of a child, irrespective of how the child had died, than to share experiences from home palliative care or home deaths in cancer. The devastation she felt, that sometimes made her feel almost insane, was recognized in the parent group and this was important to the mother. The parents she met in the bereavement group were quite ordinary mothers and fathers sometimes also feeling insane. She realized that feelings of madness were not unique. They are common to many bereaved parents (McLaren, 1998).

The mother’s feeling of stigma was recognized in the parent support group. The bereaved parents’ stories about their own experiences from workplaces made the mother feel less alienated. She realized that her loss affected others and that she had become a catalyst for other persons’ fear of death. The
members in the parent group did not need a catalyst to fear death. They already knew of death.

Together with the bereaved parents the mother could articulate her obsession, talk about her anxiety, tell about her confusion, etc. The mother realized that the other parents had suffered from the same symptoms as she had. In the parent group they shared ways of coming to terms with their symptoms. Issues that would have been impossible to describe and to raise in other groups were permitted subjects in their meetings. They shared their problem solving strategies. They could share their obsessions. They could tell about their dreams and that was beneficial even if the dreams were not analyzed professionally, as is sometimes the case in bereavement therapy (Moss, 2002). What about keeping their dead children’s belongings? How often do they go to the grave? How to celebrate the anniversaries? Where to put a picture of their dead child? What kind of sleeping pills do they take? No issue was too remote to discuss. In between they shared laughs at their own behaviour. On some occasions their meetings were almost like parties.

At first the mother participated in her parent support group on a regular basis every other week. The importance of the support from the other parents in the early phase of the bereavement could not be overestimated. Some research claims that mutual support groups are even more effective than confidants (Murphy & Lohan, 1998). There is a level of understanding that is not possible to get from those who have not experienced the loss of a child (Riches & Dawson, 1996). Even though the mother received substantial support from the parent bereavement group she would not say that the other parents in her group were her “optimal providers” (Murphy & Lohan, 1998). As mentioned before family members and friends were those who contributed the most to the mother’s support.

Research points to the risk that the participants of a self-help group will report higher levels of distress, a tendency to be more depressed and have more stress-related intrusion (Znoj & Keller, 2002). One explanation perhaps is that parents in self-help groups have more stress related intrusions before joining a group and that might be a reason for joining.

After about half a year the mother attended the group more sporadically. Murphy and Lohan (1998) wonder why the bonds established over a three-month period in a parent group do not last. The reason might be that what unites bereaved parents in a support group is that they are parents who have
lost a child. They do not share common backgrounds, interests, everyday life etc. When the mother gradually came to terms with her loss, what remained was a warm feeling of thankfulness for the support during a very hard time. After two years the mother met her parent group only now and then. As her life slowly came back to normal and although not the same as before, the need for support from the parent group decreased.

The mother’s support group was lead by a parent who had participated for many years, for her own sake but also for the sake of other parents. The mix of newly bereaved parents with those who have learnt to live a new meaningful life after the loss seemed to be of a great value. Certain stability in the group activity combined with the opportunity for particular members to go in and out of it according to their special needs made the group a safety net to be used when needed.

**Summing up**

In the mother’s first year of bereavement many person’s even from outside her family played important roles. The mother had information, learnt how to control her everyday life, came to terms with her anxiety, shared a laugh and shared experiences. The mother’s experiences of communication could be summarized as receiving *empathy*. This thick concept will be further elaborated in a separate chapter.
COMMUNICATION ACROSS GENERATIONS

Introduction

During the months and years to come after the loss of her son the mother spent much time together with her granddaughter, aged three when her father died. Through her granddaughter the mother experienced a naïve grief that comforted her. Six events from the mother’s impressionistic writings are elaborated into narratives to illustrate support from her granddaughter. They are “Swing me high”, “Caress the earth and wave to the sky”, “’A photo”, “Mother’s day”, “Only my grandmother”, and “Shared loss”. The events are shown in a time perspective in Figure 7.

The narratives are interpreted by the mother as a researcher. The aim is not to describe or analyze a child’s grief and bereavement although some theories on children’s grief are integrated into the interpretation to locate the narratives also in a framework of theories on children’s grief. It is the impact of the communication on the mother that is focused.

Figure 7. Events in an approximate time perspective
In a short term perspective breaks in the mother’s grief, actualisation of positive memories, and establishment of rituals supported the mother. In a longer term perspective the mother’s experiences that her granddaughter confirmed their family bonds and that they shared the loss were supportive, even if they were the mother’s constructions.

A narrative on communication between a granddaughter and a grandmother

Swing me high: Imagination and fantasy

I had picked up my granddaughter from the day care and we were out playing.

“Swing me high! Swing me up to Daddy!” she said when we were playing at the playground.

“High—all the way to Daddy!”

Daddy lived among the stars. He had lived there since the end of October. Now it was March, almost spring, almost light, almost possible to live again. I took part in my granddaughter’s fantasies and swung her high. I do not believe in God, I do not believe that her father is there among the stars. I was at his side when he died. We buried his ashes. But yet—in a way it was both wonderful and indescribably, utterly sad.

“Swing me high, high up to Daddy. Then I perhaps could have a kiss from him.”

Caress the earth and wave to the sky: Attachment

In the same way as she had participated in her father’s palliative care, helped out choosing the headstone and taken part in the funeral my granddaughter also participated when the urn was buried. She knew exactly where the hole was. She had put a rose on the urn when it was lowered down into the deep hole.

When we later went to the grave, my granddaughter tenderly caressed the earth on the spot, just over the hole. She quickly looked at me and her mother, as if to share a glimpse of sorrow and to have confirmation in her doings. How I wished she could caress her father!

Then the girl turned to the sky and waved a good bye to her father.

A photo: Memory

I made a print of a photo from the time before my son was taken ill. He
smiles on it. When my granddaughter saw it for the first time she looked at it very carefully.

“I wish I could talk to him”, she said.

“So do I, but it is impossible. We will have to think about what he would have said had he lived”, I said.

“I want him to be alive”, my granddaughter said. “I wish he could talk.”

“So do I. Of all my heart I want him to be alive. But it is impossible. Neither doctor K nor doctor S could find any medicine to take away the lumps in his belly. And he could not eat when the lumps were there. And you must eat to stay alive.”

My granddaughter had heard this many times before. But now she looked at me very intense, as if she wanted more information.

“You remember how tired he was. He did not have any strength to play with you. Your remember the food he got in the tube, and that he could not eat, don’t you?”

She nodded.

“I am also very, very sad”, I said and started to weep.

For a minute.

Then we talked about memories of her father.

Mother’s day: Rituals

Some days life calls upon you more than others. They are fuller than others. After such days you can feel drained of life at one moment and then feel it infusing back into all your fibres and veins in the next. You live—for good and for worse.

Such a day was Mother’s day 2005. The mere thought of it was horrifying. On this special day my son would have had his 40th birthday. Just that day 40 years ago I was a mother for the first time.

For the first time I had a baby to take care of, a child that was totally dependent on how I managed to care for him. I remember all my hope, all my good will that self-evidently ran through me.

“My child will have a good life. I will do everything in my power to make it good.”

I did not for a moment doubt my ability to fulfil this.

Forty years later I knew that my power was not enough. My son was dead and I was going to his grave together with his daughter to leave some flowers. However, I was not sure that I would not burst out into uncontrolled tears and chose to put my heart of red flowers on the grave before I picked up my granddaughter to put her heart of pink roses there.

I do not weep openly very often any more. I keep the sorrow inside. Some-
times, for short moments I have to stop and embrace the sorrow, just to be able to shake it off me and then go on living. That is how it is and I feel it will be for a very long.

We went to the grave. My granddaughter carried her little pink rose heart with both her hands, carefully and seriously. It was her father’s birthday.

“Grandma—we have to sing!”
“Yes. What song do you think we should sing?”
“Happy birthday to you, of course”, she said.

We walked as if we were in a procession, my granddaughter first, carrying the heart of roses in front of her body with both hands and I following.

“Happy birthday to you, happy birthday to you, happy birthday dear Daddy ...”, we sang.

My granddaughter put her heart on the grass on the grave. We took some dead leaves away, washed some bird droppings from the headstone. Then my granddaughter wanted me to read what is engraved in the stone; date of birth and date of death and “Endless love—endless loss”.

“What does it mean?” she asked.

My granddaughter always asks this question, likes the answers and wants to hear them over and over again.

It is hard to explain the meaning of endless love and endless loss.

“Endless is when there is no stop”, I said. “Endless love is when you love somebody so much that it will never stop. When we think about Daddy we feel how much we love him, even if he is dead. Endless loss means that we will always be sad because he does not live anymore and that we can not be together with him.”

I think that was what I said.

“We have to sing another song”, my granddaughter said.

“What song?”

“May he live, may he live for a hundred of years...” [This is a Swedish common birthday song that is translated into English to give the idea of the contents.]

I wept and my granddaughter’s eyes became large and sad. We talked for a little while about how sad we were. Hugged each other. Then we sang.

“May he live, may he live, may he live for a hundred years ...”

My granddaughter called for a cheer.

“Three cheers for Daddy. Hipp hipp hurra! Hipp hipp hurra! Hipp hipp hurra!

I cheered too—on the graveyard—on my son’s 40th birthday. I had mourned Mother’s day also with a smile.
My granddaughter caressed the earth and waved to the sky. Then we hurried home to celebrate Mother’s day.

You are my Grandmother: Family bond

The family had a very special reason to celebrate Mother’s day that year. My granddaughter’s little sister was born. A new family had been established and two children, both older than my granddaughter, were included. A new house was needed and under construction to make place for everybody. My granddaughter’s delight over her little sister was beyond limits.

Consequently, adult time for my granddaughter decreased. Her maternal grandmother, who had made a great effort in helping out especially with the care of my granddaughter when my son was ill, now had to share her love and time with the sisters. My granddaughter had to realize that her maternal grandmother was also the little sister’s grandmother. What about me then?

“You are just my /paternal/ grandmother!”

I had to correct her:

“No I am H’s, F’s and E’s /paternal/ grandmother too. Their daddy and your daddy are brothers.”

“OK then! But you are not my little sister’s grandmother!”, my granddaughter said firmly.

“No, I am not”, I confirmed.

My granddaughter was pleased. In her family I was just her grandmother on her father’s side. The little sister had another paternal grandmother. We, the paternal grandmothers, had to start using our first names to make it clear. We still use our first names.

Shared loss

My very good friend A wanted to visit me. Her visits are always welcome and of course I wanted her to stay with me. One of the days for her visit was already booked for my granddaughter’s overnight stay in my home. I asked her if she would like A to come too. My granddaughter was happy to meet A, as I had told many stories about what a nice person A is.

My granddaughter and I had also planned to visit to my son’s grave. My friend wanted to come with us.

“When we walk from the car to the grave I must walk in front of you two,” my granddaughter said, “because he is my daddy.”

Of course she could.

“Then you grandmother will come next and the last one is A,” my granddaughter continued.

We walked through the graveyard to my son’s grave in a line. Once there,
we read and talked about the words on the tombstone, as usual. We took some dead leaves away and cleaned the tombstone, as usual. My granddaughter called for a minute of silence, as usual, and we talked about my son, as usual.

As we were about to leave the grave my granddaughter said:
“Now, grandmother, you can go first. He was after all your son. Then I will follow and then A.”

I was moved. This was the first time I felt that my granddaughter recognized that both of us were close grievers, that both of us had experienced a loss. We shared the loss.

These small words of recognition meant a lot to me. I felt threads of a new kind being woven between us. I felt as if my granddaughter had recognized my loss and that she knew that I recognized hers.

**Interpretation**

The potential that lies in relations over generations is well documented (Kornhaber, 1996), e.g. university students in care education who have mentors in the group of elderly people they are trained to care for (Hamon & Koch, 1993), student teachers who are mentors for children (Rubinstein Reich, 2001), elderly people who spend time together with immigrant children (Holmberg, 2003). The benefits from these projects are most often focused on the young and the gains for the elderly are not seldom neglected (Granville & Ellis, 1999).

The attachment between grandparent and grandchild is said to be second in emotional power and influence only to the relationship between parents and children (Kornhaber, 1996; Woodward, 1997), mutually beneficial to young and older adults (Anderson, Harwood & Hummert, 2005) and to be “the most frequent and satisfying connection between these two generations” (Lin, Harwood & Bonnesen, 2002, p. 303). The grandparents and grandchildren “play important social roles in each other’s lives that often extend well beyond frequency of contact and a relationship closeness” (Mueller & Glen, 2003, p. 404). A portrait of the ideal grandparents shows a loving group, worthy of respect, teller of family stories, backbones of family functioning, and give positive pictures of older people and their lifestyles, perhaps more ideological than real (Stovall Hanks, 2001).

There is a need of further research on intergenerational issues. Demographic changes have increased the importance of grandparent role in family life,
implying that grandparent–grandchild relationships ought to be studied in a family context (Crosnoe & Elder, 2002). Since the 1980’s more and more people spend longer time as grandparents than before (Pruchno, 1995).

Research using qualitative data “might be the best method for investigating the different perspectives of grandchildren and grandparents” (Crosnoe & Elder, 2002, p. 1095). The narrative above is embedded in a family setting, also touching upon the relationships over three generations, from the perspective of the elder generation, as in most research on intergenerational relationships (Holmberg, 2001).

**Imagination and fantasy**

In times of stress people tend to regress developmentally. That is what happened to the mother when she played with her granddaughter after her son’s death. Even if she as a non believer did not think her son was in Heaven, she liked the thought and enjoyed her granddaughter’s fantasy play, when she was asked to swing her granddaughter up to the sky, so that her granddaughter could give her father a kiss. For some short moments the fantasy comforted the mother. As mentioned in a previous section, the tragedy that her son was dead was, in the months just following the death, almost surreal and not yet integrated into her. To pretend for a short moment that her son was sitting on a star looking at her and his daughter playing was comforting to the mother.

“Regressive fantasy may be mobilized as a kind of psychic protection when someone is faced with a present-day situation which feels unbearable or seem insoluble” (Knox, 2003, p. 224). Fantasies should not, however, be intermixed with repression, that according to a contemporary psychoanalytic model can be thought of as “the intentional keeping out of consciousness the meaning of a memory ...” (Knox, 2003, p. 208). As mentioned before suppression might also be seen as a coping strategy (Stroebe, 1992–1993). The mother could for a short moment have an inner dialogue: “What if he is up there, seeing us playing?”, but she soon answered herself: “His is not. He is dead.”

Even if the mother was a non-believer she did for some time contradictorily move around in a “terrain” of faith” waving to Heaven and “a God she did not believe in” (Walter, 2002, p. 137). The terrain referred to consists of formal religion, folk religion, explicit secularism and implicit secularism. The last exemplified by “When you're dead, you're dead” (Walter, 2002, p. 137).
To the mother it was painful to live up to her implicit secularism, and she found momentary peace in playing her granddaughter’s fantasy plays.

To her granddaughter, however, the construction of the fantasy of her father sitting on a star looking down on her, might well serve an essential role in her construction of a growing sense of identity and relationship (Knox, 2003) and an unconscious “working model” in her development (Knox, 2003, p. 219). Her identification of herself as a fatherless child and the new relationship to him was yet to be developed. The granddaughter’s age relevant magical and wishful thinking in this process (Crace, 1995; Goldman, 2004; Gustavsson & MacEachron, 2000) gave the mother short moments of comfort. As they spent much time together there were many such moments.

Permanency is developmentally difficult for younger children to grasp, and adults must reinforce the reality that the dead person will not return (Schoen, Burgoyne & Schoen, 2004). Research is consistent about the importance of answering children’s questions honestly, patiently and in a language that is appropriate to the child’s developmental stage (American Academy of Pediatrics, 2000; Gustavsson & MacEachron, 2000). Children need to know the age-appropriate truth about death Goldman (2004) or rather they ought to be talked to in a way that is appropriate to their developmental stage and their age might be a guideline to see it (Gustavsson & MacEachron, 2000).

But, what about honesty? The mother was concerned. Did she cheat on her granddaughter when she waved to a son she had buried and to a Heaven in which she did not believe? In an article on telling the truth to children about a parent’s suicide the issues of not telling the whole truth to young children is discussed. “... our needs as grown-ups to share truthfully with the child the specific nature of a parent’s death must not be confused with the child’s current needs” (Cain, 2002, p. 126). The mother dealt with the dilemma to be honest and still not disturb her granddaughter’s naive belief that her daddy was in Heaven on a star, by saying that it was nice to think that her father could see what they were doing, but that she could not have a kiss from him because he was dead. At the same time the mother imposed her realism on to her granddaughter, telling her that she could not kiss her father, thus disturbing the fantasy. Even so, the mother hoped she had created a way for her granddaughter to share feelings of grief, as even sharing thoughts and feelings about death recognizes children as mourners (Goldman, 2004).
The granddaughter attended her father’s funeral, as did all her five cousins on her father’s side, aged 3 to 11 years. Her mother had prepared her thoroughly for it. She had met the priest, visited the church, and read about funerals in children’s books (e.g. Stalfelt, 1999). To prepare children for and invite them into the family’s grieving experiences and processes are important issues in children’s grief process (e.g. Charkow, 1998; Dowdne, 2000; Holland, 2004; Hurd, 1999; Ledezma, 1994; Schoen, Burgoyne & Schoen, 2004). The granddaughter was involved in as many rituals as possible including burying the urn.

Adults often want to protect children from painful experiences (Klein & Alexander, 2003; Thompson & Payne, 2000), but sometimes leave them confused and alone with their fears and fantasies (Charkow, 1998; Stokes et al., 1999). Children want to know about the cause of the death, lifespan, doctors, the dead body, and feelings of grief. Bodily functions permanently ceasing appears to be an important aspect that children need to investigate. Children’s questions on death can be difficult to answer even for a doctor. Particularly emotion-focused questions are challenging whereas questions on biomedical matters seem to be easier to talk about, not only for a grandmother but also for a doctor (Thompson & Payne, 2000). Open and honest communication with the child about the death and its impact on the family are salient factors to healthy childhood mourning (Greeff & Human, 2004; Hurd, 1999).

Children in the age between two and seven are vulnerable due their limited cognitive understanding (Schoen, Burgoyne & Schoen, 2004). They have their naïve theories to build on when understanding the world. “Their questions reflect their level of understanding of death, but often, more importantly, the meaning of their loss” (Thompson & Payne, 2000, p. 95). Children’s speech is social and communicative in both origin and content, and not merely a personal egocentric affair (Thompson & Payne, 2000). “Children actively ‘construct’ their knowledge of the world” (Thompson & Payne, 2000, p. 75).

And again—how to tell the granddaughter that her father’s body was burnt and that the ashes were put into an urn and buried? Her grandmother (the mother) could not get herself to tell her granddaughter the truth about her father’s ashes. It was all still almost surreal to the mother.

However, the episode on the graveyard when her granddaughter caressed the earth had a positive impact on the mother. In a way it was as if her granddaughter by caressing the earth caressed her father, and this magic was conveyed to the mother. The movement of the little hand and the tender look...
in the granddaughter’s face made the mother feel how close the granddaughter was to her father. To the mother the scene was extremely emotional, warm and sad at the same time. It was heartbreaking to see how her granddaughter caressed the earth but a comfort to realize that there was a bond between the daughter and her father, even if he was dead. The love that the father, her son, had given to his daughter, she kept and showed. The mother was sad and moved, but supported in her grief by the knowledge that her granddaughter would remember her father as the loving father he had been. The glance at the adults from the granddaughter was perceived by the mother as a way for the granddaughter to share an experience, to be confirmed by the adults and to build a joint understanding.

**A listener**

To do memory work alone and to remember by sharing with others maintain a continuing bond with the person who died (Goldman, 2004) and can be important, according to a contemporary model of grief (Davies, 2004; Moules et al., 2004). Sharing artefacts, e.g. photos, drawings, books, with others helps bereaved parents’ adjustment toward a manageable relationship with their child’s memory. These objects of discourse help provide continuity in the parents’ search for a form of reconciliation after their loss (Riches & Dawson, 1998). Like children (Glazer & Marcum, 2003; Le Count, 2000) parents need listeners but friends might be upset or tired of hearing (Dean et al., 2005; Goldman, 2004). The granddaughter was a most interested and attentive listener.

The mother could tell stories about her son. She could remind her granddaughter about memories, thus contributing to preserve the granddaughter’s own memories of her father. Her granddaughter was as children often are (Woodward, 1997) intrigued by stories about her father, when he himself was a child. The mother had opportunities to be an oral historian and confidant and could add stories about her son’s childhood and adulthood to her granddaughter’s portrayal of her father. Hence, the storytelling was beneficial to both of them in their bereavement.

**Rituals**

Keeping rituals and habits is important in children’s grief process (Greeff & Human, 2004) as it is in adults’. Rituals related to visits to the grave were established in the family by the granddaughter but also by her six year old paternal cousin, who was the first one to proclaim a minute of silence, when the family visited the grave. After some time it became a ritual.
Even if rituals, e.g. celebrating anniversaries by visiting the grave, might be beneficial for the grief process, they can also revitalize the pain of the loss (Klein & Alexander, 2003). To the mother, Mother’s day was such an occasion. The already established rituals helped out; the minute of silence, reading the headstone, picking leaves etc. The songs common on birthdays were sung even if the contents were a paradox. However, the choice also made the mother smile (between tears). The mother knew when to leave the grave, i.e. after the granddaughter waved to the sky.

Family bonds

The roles in the family changed when the son, a significant family member, died. His widow became head of the core family, a role that was earlier shared between the son and his wife. She had to take on the main responsibility for their daughter.

After some time a new core family was established and the granddaughter got a little sister. It is a great change to have a little sister, a stepfather, and step-siblings, something that the granddaughter got about two years after her father died. No wonder that she became uncertain about the mother’s (her grandmother’s) role in her life. The granddaughter’s family now was a “blended family” (Mills, 2001a, p. 405) that can make the grandparenting more complex (Mills, 2001b). Furthermore the mother had five more grandchildren, and the larger the number of grandchildren the more difficult it is for a grandparent to be a significant figure in each of their lives (Mueller & Elder, 2003). The granddaughter knew her cousins and was fond of them, but sometimes there were situations, when sharing her grandmother (the mother) was hard. The mother felt that her granddaughter wanted the exclusive right to her. The unbroken “circle of trust” (Goldman, 2004, p. 184), the attachment, between the mother and her granddaughter, had to be re-confirmed in the new family situation over and over again.

The importance of maintaining a warm and caring environment for a grieving child is essential (Schoen, Burgoyne & Schoen, 2004). During the past three years since her father died his family members had made great efforts to help each other. The wife as the primary and the granddaughter’s two grandmothers as secondary attachment figures tried to establish an environment in which the granddaughter could feel safe. It was up to the adults surrounding her to accommodate to her as caring adults and guide her through the process of grieving (Le Count, 2000).
To the mother it was also a way of keeping the promise she gave her son when he was dying, a way of continuing the bond to her son, not unusual in bereaved persons (Stroebe, 1992–1993; Stroebe et al., 1992). She felt privileged to be a part of the family’s “secure base” (Waters & Cummings, 2000, p. 167) and as a family member to be able to “provide a source of redefined attachment” for her granddaughter (Schoka Traylor et al., 2003, p. 594). The granddaughter realized and reinforced the impact of their biological attachment, indicating that to her the relation between her and the mother (her grandmother) was valuable.

**Shared loss**

The question whether preschool aged children have the ego capacity to undergo a successful mourning process has been raised. Contemporary notion is that children can and need to grieve, and need an allowing supportive environment in the grieving process (Charkow, 1998; Cohen et al., 2004; Cooper, 1999; Curtis & Newman, 2001; Dowdney, 2000; Thompson, 1997). The mother never doubted that her granddaughter grieved her father.

There are some indications that accommodation to each other is the most powerful unique predictors of intergenerational relational solidarity, i.e. communication satisfaction, liking and emotional closeness between grandparent and young adult grandchildren (Harwood, 2000). Accommodation does not have to been shown in words. Not until the granddaughter had organized the order in which they should go to and leave the grave did the mother experience that her granddaughter accommodated to the mother’s grief, in action as well as verbally. The mother felt that her granddaughter acknowledged her as a bereaved parent. The mother felt her empathy, important for successful outcome of grief (Goodman et al., 2004). The granddaughter knew beforehand that the mother was sad, she had seen her sometimes weeping, but never before had she openly recognized the mother as a grieving parent. Now the mother felt as if they both knew that they shared the loss.

**Summing up**

In the short term perspective the communication between the mother and her granddaughter during the three years following her son’s death gave the mother some breaks in her grief, a listener to stories about her son and support when visiting her son’s grave. In a long term perspective the confirmation of the established attachment between her son and his daughter was comforting to the mother. Family bonds between the mother and her granddaughter were confirmed by her granddaughter and the mother experienced
her granddaughter’s recognition and acknowledgement of her as a parent in
grief as empathic.

A summary of the interpretations

The study is built on data on a mother’s experiences of a four year long
process, beginning with her son’s diagnosis of leiomyosarcoma until three years
after his death. The communication is described as experienced by the mother
and analyzed from her perspective. The focus is on experiences of communication
that had a positive impact on her as a lay palliative caregiver and a parent.
In Figure 8 significant concepts that emerged from the mother’s writings and
that were illustrated in the narratives are listed as an introduction to a
discussion of empathy in different contexts.

Hope and disavowal versus fear and despair
as an obstacle for communication

<table>
<thead>
<tr>
<th>Recognition</th>
<th>Acknowledgment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respect</td>
<td></td>
</tr>
</tbody>
</table>

Communication in action between
family caregivers and a palliative
home care team

| Trust | Flexibility |
| Continuity | Accessibility |
| Empowerment |                |

Words that made a difference in
communication in grief and
bereavement

<table>
<thead>
<tr>
<th>Information</th>
<th>Control</th>
</tr>
</thead>
<tbody>
<tr>
<td>Friendship</td>
<td>Shared experiences</td>
</tr>
</tbody>
</table>

Communication across generations

| Breaks in the grief | Memorizing |
| Rituals | Confirming family bonds |
| Shared loss |                |

Figure 8. A summary of the positive experiences of communication
EMPATHY IN DIFFERENT CONTEXTS

The mother experienced communication that made a positive difference to her in the palliative home care and in her grief and bereavement in a number of contexts; the welfare system at large, including the palliative home care team, the primary health care system, and the social security system, among friends and bereaved parents. Foremost, the mother was supported by her family. Empathy might serve as a common denominator for the support that made a positive difference to the mother and fostered her reconciliation process that will be addressed later.

In this chapter empathy experienced by the mother is located in different contexts. Some notions on a death concealing society will be made, as all the experiences of communication are situated in society. The need for a society in which death to a certain extent is concealed to educate its people on death related issues is touched upon.

The mother and her family were socio-economically privileged and were fairly well aware of their societal rights. Whether members of less privileged and less articulate families would have the same access to care and support as the mother and her family will be discussed.

Figure 9 shows contexts where the communication was carried out. It is quite obvious that the communication between the palliative home care team and the mother decreased in frequency over the years, as did the communication between the hospital, where her son was treated for his cancer. The communication between the mother and her family doctor during the son’s illness and the first year of her bereavement will probably have some impact on their communication later on. The same goes for the communication between the mother and her closest friends, i.e. the mother's loss and the support from her friends will most likely influence their future relationships. “Back to new
usual” in Figure 9 implies that the mother no longer needed extrinsic inputs. Even her relationships with others were on the whole no longer quite the same as before.

The same goes for the communication within the family. What they shared during the son’s illness will most certainly always have an impact on their future relationships but this is not an issue for the study. Instead the deepened family bonds are exemplified by the mother’s experiences of communication between herself and her granddaughter.

![Figure 9. The contexts of communication in a time perspective](image)

**Figure 9. The contexts of communication in a time perspective**
Empathy

Empathy is a complex concept, implying that its definition is often imprecise. Empathy origins from the Greek word empatheia, made up by *en*, for in, and *pathos*, for feeling and suffering. Affective empathy refers to emotional understanding and cognitive empathy to intellectual understanding (Lawrence et al., 2006). Predictive and situational empathy respectively refer to the ability to predict reactions and to the ability to perceive and react to other person’s feelings in a specific situation. Trait empathy is seen as part of the personality. (Määttä, 2006.)

Empathy relies on the use of shared representations, that is an overlap between representations of the self and other, both of which are integral to developing a robust and clinically relevant account of empathy (Lawrence et al., 2006). In the following, cognitive empathy, i.e. understanding and predicting someone else’s mental state as well as affective empathy or experiencing an emotion as the result of someone else’s emotional state will be related to support received by the mother.

Empathy is also said to either be possible to learn or as a way of being (Rogers, 1975). Rogers considers empathy as an act of will and thus possible to control. Contemporary understandings seem to advocate, that empathy is used to describe a neutral friendly and helpful manner, not to be confused with liking someone, and describes the facets of being empathic to another person as

- entering the private perceptual world of the other
- being sensitive
- temporarily living the other person’s life
- sensing meaning of which the other person is scarcely aware
- communicating the sensing of the other person’s world
- frequently checking with the other person as to the accuracy of these sensings
- being guided by the responses from the other person.

Empathic persons lay aside for the time being their own views and values in order “to enter another’s world without prejudice” (Rogers, 1975, p. 3). Rogers emphasizes that empathy is not the only important process in growthful relationships. In ordinary life congruence is perhaps the most important element as a basis for living together in a climate of realness. Congruence between persons allows for letting other people know who you are and it may involve confrontations, straightforward expression of both negative and
positive feelings. It is an element in a symmetric relation. In specific situations caring or prizing may turn out to be most significant, e.g. between parent and child, physician and very ill patient. In situations where a person is “hurting, confused, troubled, anxious, alienated, terrified; or when he or she is doubtful of self-worth”, an empathic stance provides illumination and healing, according to Rogers (1975, p. 9).

In the hypothesis that Rogers set forth in the late 1950’s he identified six necessary and sufficient conditions for “constructive personality change to occur”, irrelevant of what techniques were used (Rogers, 1957/1990, p. 221):

1. Two persons are in psychological contact.
2. The first, whom we shall term the client, is in a state of incongruence, being vulnerable or anxious.
3. The second person, whom we shall term the therapist, is congruent or integrated in the relationship.
4. The therapist experiences unconditional positive regard for the client.
5. The therapist experiences an empathic understanding of the client’s internal frame of reference and endeavours to communicate this experience to the client.
6. The communication to the client of the therapist’s empathic understanding and unconditional positive regard is to a minimal degree achieved.

Furthermore, these conditions must exist and prevail over a period of time. It was however shown that the hypothesis was hard to test. Firstly, studies often used therapists who exhibited minimal levels of the conditions. Secondly, the client’s perception was not normally taken into account, and finally not all the core conditions were taken into account. “Rogers did not suggest that each condition was sufficient but that all were sufficient. When all the conditions are present and the client perceives them, Rogers said that positive change will occur” (Kirschenbaum & Jourdan, 2005, p. 42). Of the core conditions congruence is the most difficult for therapists to get right, perhaps due to the fact that establishment of congruence is to a greater extent a process that involves the client and is thus mutual, whereas positive regard and empathic understanding might be shown by the therapist without the client’s perceiving it. More research is needed to learn about how congruence can be used most helpfully in counselling and psychotherapy (Sachse & Elliot, 2001).

Later research suggests that the support for the “core conditions” of positive regard, empathy and congruence, may neither be sufficient nor necessary, for
all clients. However, these “core conditions are helpful to extremely helpful with virtually all clients” (Kirschenbaum & Jourdan, 2005, p. 43). Even if Rogers’ core conditions are still considered important ingredients in therapy a specific therapeutic approach or technique seems to be abandoned in favour of a move toward eclecticism and integration of different schools of thought. Many more therapists, even if not identifying themselves as primarily or partially person centred, nevertheless incorporate Rogers’ core conditions as important ingredients in their own therapeutic approach (Kirschenbaum & Jourdan, 2005, p. 47).

According to Stein’s theory, empathy develops in three stages. In the first stage we try to put ourselves in another’s place by listening, reading facial expression etc. In the second stage the empathizer identifies with the other, by remembering own experiences or a similar event. In this stage intellectual understanding is replaced by emotional understanding, and the empathizer identifies with another person. In the last stage the affinity that was felt in the second stage is turned into sympathy and the empathizer again stands side by side with the other person. (Määttä, 2006.) In Barrett-Lennard’s model of empathy seven stages are included (in McLeod, 1999): 1) preparedness, 2) client expressiveness, 3) therapist engagement with the detailed contours of the client’s story-world, including conceptual empathy, self-experiential empathy, imaginative imitation, and resonance, 4) the counsellor’s demonstration and communication of empathic understanding, 5) client receptivity, 6) the unfolding of the client’s story, and finally 7) beginning the next cycle. Questions have however been raised whether the term empathy is suitable for labelling this cyclical process. Could it not be labelled “therapist engagement with the client” or “co-construction of shared meaning”? (McLeod, 1999, p. 389).

In a society characterized by a high degree of collective, communal experiences the need for the concept of empathy, if used for situations in which the capacity of one person to understand the feelings and experience of another is problematic, does not emerge. In modern industrial mass society, collective experiences became fragmented and people are to a lesser extent related to each other by means of kinship, place and shared history and “it is necessary to work at understanding the other” (McLeod, 1999, p. 389). Furthermore, in the 20th century, during the expansion of capitalist economies the idea of an “empty self” emerged, another rationale behind the emergence of psychotherapy and professional counselling (McLeod, 1999, pp. 389–390). This way of understanding empathy as the relation between an active empathiser and passive object-of-empathy was, in the earliest usage of the term, also used to
describe the capacity of a person to respond to the qualities of a work of art (McLeod, 1999.) However, contemporary research on empathy stresses the mutual process.

A prerequisite to show empathy is to recognize and acknowledge a person’s feelings. This does not imply that we can experience the other person’s feelings as experienced by them. A person who has experienced grief seems however more likely to be able to recognize another person’s grief. Remembering own experiences is a prerequisite to empathy. A person who has not experienced a specific feeling can still respect the other person feelings and show an intellectual understanding. Most writing and research on empathy acknowledge both its cognitive and affective components. (McLeod, 1999.)

As mentioned, the question whether empathy can be taught and learnt is raised. If remembering own experiences is a prerequisite for empathy, then it would be hard to say that it is possible to teach empathy, at least in relation to a specific experience. On the other hand, empathy might be seen as a continuum and not as either or. Caring with respect, sympathy and intellectual understanding can “pave the way for the empathic process” (Määttä, 2006, p. 7). Especially in challenging situations such as palliative care, grief and bereavement this calls for experienced professionals. “Experience, is for me, the highest authority”, Rogers wrote, and continued (1961/1990, p. 25):

> Neither the bible nor the prophets—neither Freud nor research—neither the revelations of God nor man—can take precedence over my own experience.

Even so, Rogers did not perceive his experience as authoritative as experiences are infallible, and can always be checked in new primary ways.

In the following, empathy will not only be discussed in a professional empathic context, e.g. counselling and psychotherapy. Empathy is considered a continuum of support for the mother that had a positive impact on her. On an institutional level empathy can be expressed by rules and regulations that are built on an intellectual understanding of human experiences and the ideology of a welfare state. In a palliative care setting, empathy with patients and family caregivers can be built on the professionals’ experiences of dying and death, even if the professionals do not have their own experiences of losing a loved one. In the forthcoming, this type of empathy will be said to be based on compassion. Yet another level of empathy, based on shared experiences and identification, according to Stein’s stage theory, is possible. A final level of
empathy that will be discussed is empathy to self, including an understanding and acceptance of the self, as described by Rogers (1942/1990). First however, some notions on death and dying in a contemporary Western society will be made, as it is in such a society that empathy was shown to the mother and in which the narratives are located.

Death, grief and bereavement in contemporary Western society

“One of the functions of cultural narrative is to police grief” (Klass & Goss, 2003, p. 791), that is to pressure its members to make their narratives congruent with the larger social narrative even to the extent that “it is often impossible to separate an individual’s grief from culturally required mourning” (Rosenblatt, 1993, p. 104). Despite the intercultural variety, consistent themes and similarities in relation to death, e.g. crying, have been found across cultures. All over the world those who experience the death of a loved one are upset in ways that others can recognize. Across cultures the loss of a specific person also implies other losses, though different in between cultures, and across cultures people give meanings to death in different ways. (Rosenblatt, 2003.) Cultural differences appear to be more related to bereavement rituals and practices rather than to basic human emotional responses (Klein & Alexander, 2003).

Cross-cultural grief literature offers a bereaved person both a sense of common humanity with all grieving humans and a sense that whatever one’s culture or cultures, there are many bereaved people around the world who are feeling, thinking, and doing things that would not fit one’s own situation. (Rosenblatt, 2003, p. 860.)

Many held assumptions about death, grief and bereavement are rooted in research conducted in the United States, and are thus formulated from a Western world perspective. From such a perspective it has been claimed that modern Western society is death-denying (Johnson, 2004; King, 2003). In such a society “never before have humans been able to kill so many people so efficiently or to forget them so completely” (Geary, 1994, pp. 1–2). Death is said to be denied as a normal life experience (King, 2003) and very much removed from contemporary, everyday life (Charkow, 1998). The “good death” is described as private and hidden (Raunkiær, 2007). Members in a death-denying society seldom know what to say to people who are dying (McNamara, 2004; Sanders, 1992; Schoen, Burgoyne & Schoen, 2004). Also “the sorrow that follows death” is said to be hidden within the family unit or
within the grieving person’s own mind (Clements, et al., 2004, p. 150). We are taking the “D”-words out of our everyday vocabulary using “end-of-life care”, or time-efficiently, “EOL” for the care for the dying. “Hospice” care is becoming “palliative”, palliative is taking the place of “terminal”, and dying persons are merely “life-threatened” (Wass, 2004, p. 303) or “chronically ill”, as the son in this study was characterized by his oncologist, some weeks before he died. In the 1970s Ariès used the expression that death is “unnameable” (Ariès, 1974, p. 106) and “forbidden” (ibid., p. 85).

A single person is missing for you, and the whole world is empty. But one no longer has the right to say so aloud. (Ariès, 1974, p. 92.)

Death became unnameable, and regarded as “wild” in the modern society, “hidden within institutions and managed by the doctor and hospital team who strive to obtain from their patients an acceptable style of living while dying” (Hart, Sainsbury & Short, 1998, p. 66). In this wild death discretion is the “core element of dying with dignity” (Hart, Sainsbury & Short, 1998, p. 66), and those who were dying and grieving in the past were far less isolated than today (Hart, Sainsbury & Short, 1998).

In her classical work Kübler-Ross described the modern process of dying as gruesome, lonely, mechanical and dehumanized (Kübler-Ross, 1970) and identified stages in the dying process. The final stage being the dying person’s acceptance of death. Acceptance is not to be intermixed with “a happy death”. Instead the acceptance of death is said to be “a final stage wherein the denial, anger, depression and emotional struggle to resist the ending of life had been resolved, ‘unfinished business’ had been attended to, all necessary words spoken, preparations and farewells made”, all leading to peaceful death (Hart, Sainsbury & Short, 1998, p. 68). There are some weaknesses and dangers in such a stage theory. The implementation by health professionals might lead to a failure to recognize cross-cultural differences, to an inconsistency in the diagnosis of stages and to differences in the interpretations of the behaviour of dying patients (Hart, Sainsbury & Short, 1998).

In contemporary literature on palliative care, death is sometimes described as dignified, good and peaceful. If death is defined as the endpoint of a dying trajectory then the expressions “dignified death” and “good death” should however be avoided. The concept “meaningful death” (Forbes & Rosdahl, 2003, p. 213) seems even more dubious. The concept of dignity is perceived to be close to the family members’ conceptions of the patient’s autonomy and
“power to maintain integrity as a human being” (Miettinen, Alaviuhkola & Pietila, 2001, p. 270). Rather than using the expression of dignity in relation to death and dying we should talk about palliative care in terms of the dying patient’s state of mind, desires, and autonomy (Sandman, 2002). The late modern discourse of death stresses the ideals of a unique person living while dying, palliatively cared for as long as possible, benefiting from a social network and a multidisciplinary team, having control over the dying process and possibility to perform autonomy (Raunkiær, 2007). A patient who is angry, non-accepting, and non-compliant would then consequently become a deviant patient, who violates the established norm (Hart, Sainsbury & Short). Howell and Brazil use the expression “quality of dying experiences” including even the subjective expectations and values of the patient’s family members (Howell & Brazil, 2005, p. 25). The above mentioned indicates that researchers have different connotations of significant words in describing death.

Yet a reason not to use the expression “good death” is that before a patient is dead there is still hope to do things to make his life better, even if not to the extent that his life is good. Death puts a stop to all care and all hope for those who want to make a difference, family members and professionals alike. Another reason not to use the expression is that it is a thick concept, including evaluative, normative as well as descriptive elements (Hart, Sainsbury & Short, 1998; Sandman, 2002). A further reason is that it might imply that there are good and bad patients and thus contribute to the caregivers’ attempts to “shape the lives of dying people”, as mentioned before (Hart, Sainsbury & Short, 1998, p. 65).

Western modern society’s “chief attributes” (Stroebe et al., 1992, p. 1206) are an emphasis on reason, observation and a faith in continuous progress. In such a society the “breaking bonds” hypothesis serves its goal of directedness, efficiency and rationality, and the attempt to restore proximity to a lost loved one is inappropriate and non-functional (Stroebe et al., 1992). The energy invested in the lost person should be transferred to a new one, for the bereaved to be able to regain these energy resources.

The breaking bonds hypothesis is questioned in the Western society by contemporary research on grief. There are indications that a majority of widowed persons do not plan to break with their past but try to integrate the loss experience into their life-style and carry on much as before (Stroebe et al., 1992). Parents, who lost their sons in the two Israeli wars, went about their
daily activities much as usual, somatic complaints were no longer excessive, and their psychological adjustment seemed normal after a few years. On a deeper level however, the parents remained very involved with their sons. This shows that despite apparent adjustment, bereaved parents of adult sons showed, over the years, virtually no change in their preoccupation with the deceased and the effect of loss on their inner lives did not subside (Rubin, 1993). A woman who loses a child in the war is described as “a pregnant woman who carries a dead foetus in her womb”, as expressed by an Israeli poet (Yehudah Amichai, 1985, in Malkinson & Bar-Tur, 2000, p. 249), indicating that parental grief is also very private. Studies like these falsified the breaking bonds hypothesis, and a contemporary post modern perspective is added to the modernist view of grief and bereavement. Stroebe et al. (1992) stress the multiplicity of perspectives, a “dual process model” (Neimeyer & Gamino, 2003, p. 850). In a modernist perspective retaining ties to the lost one was symptomatic to emotional problems and mental illness, whereas the post modern perspective, influenced by a romantic perspective, advocates the bereaved to hold on to the departed loved one, and in a dual process oscillate between loss-oriented and restoration-oriented strategies.

Even if a “clinical lore”, that pressures individuals and families to express emotions as a means of resolving grief (Klass & Goss, 2003, p. 792), the concealing of death is still a phenomenon in some late modern Western societies, supposedly because the late modern ideals of dying and death are not actualized in everyday life until we face death, our own or our loved ones. In some Western countries it is easier to conceal death than in others. The rhetoric of a death denying or death concealing society is not applicable to Western societies that have been haunted by wars during modernity. In some countries it is not possible to conceal or deny death as it is an everyday experience to many people. Israel has for instance a bereavement culture or a “collective representation of individual grief” (Klass & Goss, 2003, p. 793). Its emergence has been caused by the almost 19000 young Israelis who have been killed during the 50 last years of war, and the society has developed a collective national framework, within which death to a certain extent is talked about (Malkinson & Bar-Tur, 2000).

The contemporary discourses on death, grief and bereavement advocating a personalized living while dying and a dual process of grieving on one hand and the Western society as concealing death on the other point to a need for public education, attending to both scientific and humanistic goals (Murphy, 2000; Sanders, 1992; Wass 2004). The importance of education for those who work
with the issue of mortality is stressed in the research literature (Blasszauer & Palfi, 2005; Hylton Rushton, Spencer & Johanson, 2004; Wass, 2004). There seems to be little empirical understanding of the relationship between the education of palliative caregivers, the practice of palliative care and the personal moral attitudes that are needed in care for the dying (Olthuis & Dekkers, 2003). One reason is of course that it is, as mentioned before, extremely difficult to conduct studies on the dying. In a study on nurses’ experiences of a child’s death half of the respondents meeting grieving families reported an inability to support the family particularly well (Kaunonen et al., 2000). One must also take into consideration that not all members of the health care profession are willing or able to effectively address end-of-life issues (Owens, 2004).

End-of-life care is minimal or absent in medical textbooks and in nursing education (Wass, 2004) and there is evidence that “counsellors feel intensely uncomfortable when faced with client issues concerning grief or impending death” (Wass, 2004, p. 296). Only half of the students in the health professions are offered a full course related to death; the rest typically are provided death-related content only in a few lectures, according to Wass (2004), although improvement in palliative care would eventually improve health care as a whole (Olthuis & Dekkers, 2003). A threefold goal of death education is recommended; cultural education, suicide/violence prevention and death education as antidote (Wass, 2004). According to Sanders (1992) to learn about the grieving process after a significant loss is important. Eight crucial factors should be included in training services for students embarking on professions dealing with death, dying and bereavement (Tramonte, 1996, p. 5):

(1) Communication;
(2) Values;
(3) Concept of the Family;
(4) Religious Beliefs;
(5) Attitudes Toward the Body;
(6) Attitudes Toward Death;
(7) Bereavement, Grief, and Mourning Practices; and
(8) Funeral Practices

Furthermore, death-concealing societies are said not to educate their children about death before it is encountered. Teachers and parents are reported in an Irish study to be uncomfortable talking to children about death and further teacher training would be desirable (McGovern & Barry, 2000). Stokes et al.
ask whether it is reasonable that a health culture that reacts positively to all births advocates “the rationing of services following the end of a life” (1999, p. 305). Sanders recommends that death education starts with children, “because they have a wonderful sense of compassion” (1992, p. 26). There is also limited research on adolescent bereavement and interventions in a school setting (Lenhardt & McCourt, 2000). There are some indications that young adults who have lost a parent and had dealt with death in their day-to-day living context had lesser tendency to be threatened by death (Meshot & Leitner, 1995).

The challenges for a welfare state to care for dying patients and their family members are numerous. One reason is that there is “a poor evidence base for most of the practice” (Riley & Ross, 2005, p. 736) and thus “evidence-based palliative care is more often the exception than the rule” (Lipman, 2000, p. 3). Evidence-based practice is defined as:

Integration of best evidence with clinical experience and patient values. It involves obtaining research evidence and combining the evidence with clinical experiences, available resources, and patient preferences to determine the best care for the patient. (Cliff et al., 2004, p. 189.)

The same is relevant for the area of bereavement that lacks a “formidable evidence base” (Forte et al., 2005, p. 8) and formal assessment (Jordan & Neimeyer, 2003). Good evidence exists only on pharmacological treatment of depression in the context of bereavement (Forte et al., 2005). “There is so much missing evidence!” (Miller & Crabtree, 2005, p. 613). In the methodological discussion some reasons for the lack of evidence in the fields of palliative care and bereavement were discussed. Miller and Crabtree suggest the use of two strands in medical research, one strand addressing meaning, power and complexity captured by qualitative analyses and the other providing quantitative measurements.

The qualitative and quantitative strands twist and spiral around the questions in an ongoing interaction, creating codes of understanding that get expressed in better clinical care. (Miller & Crabtree, 2005, p. 613.)

It seems as if research on death and dying should address the four questions: What is going on with our bodies? What is happening with our lives? Who has what power? and What are the complex relationships among our bodies, our lives, our ecological context and power? These questions are “infinite and
challenging”, the answers are context dependent and methods of numeracy, literacy, policy and ecologically thinking all contribute to answers. (Miller & Crabtree, 2005, pp. 614–615.)

In this study the son and his family benefited from care from a palliative home care team, in which the physician and the nurses were specialized, experienced and had chosen to work with dying patients and their family caregivers. The family faced death together with nurses, who opened up also for a communication about death in the home. The mother’s fear and despair of death and need to talk about it were recognized, acknowledged and respected in this atmosphere.

**Institutions as a base for empathy**

A definition of welfare is coined by Tengland (2006a, pp. 159–160): Welfare is “any factor (state or process), inner or outer, that contributes to the (positive) quality of life (well-being or desire-fulfillment) of an individual, or that typically contributes to the (positive) quality of life of a population.” A welfare state then is a state that positively contributes to the quality of life of the majority of its population. The mother experienced positive contributions from the state in relation to the palliative home care of her son, her grief and bereavement, carried out by hospitals, primary health care, palliative home care, social security system and through psychotherapy. This kind of support, will be called institutionalized empathy. This empathy, founded on an ideology of quality of life, equal values and equal rights for the individuals in the society, is built into the Swedish welfare system. Welfare should be distributed in a fair way.

The issue of equality in palliative care is discussed in relation to cultural differences, globally and nationally (Wass, 2004). The unequal distribution of health care on the global level is beyond doubt. In all, 90 percent of all medical research is undertaken on diseases that cause 10 percent of the global disease burden (Singer & Bowman, 2002). Regarding developing countries “data on capacity for delivering quality end-of-life care” are hard to find (Singer & Bowman, 2002, p. 1). Some figures are found regarding the Asia Pacific Hospice Palliative Care Network, saying that India, Indonesia, Korea, the Philippines and Thailand are not covered by any palliative care services for patients with cancer, whereas in New Zealand the coverage estimates 83 percent (Goh, 2002). In these parts of the world death is most often seen as an integral part of life. An example of global inequality related to parental loss is the eco-
nomics concerns for elderly parents in Thailand and other countries. When losing an adult child parents risk losing the family provider. This problem did not even occur to the mother in the study.

Also within Western countries the inequality is discussed in relation to palliative care. In the UK Black Caribbean caregivers fare worse and need greater financial help than white caregivers (Koffman & Higginson, 2003). Black and ethnic minority people are found to use hospice and palliative care to a lesser extent in relation to their numbers (Bradburn & Maher, 2005). Less educated family caregivers tend to experience more emotional stress (Cameron et al., 2002). The patients’ educational level has an impact on their knowledge of palliative nursing service. Caregivers from non-metropolitan areas knew of fewer community services than did caregivers from metropolitan areas and young, unmarried caregivers had little knowledge of available services in a study by Burns et al. (2004). Yet another difference is noted: significantly greater awareness of dying is found in upper class (Hinton, 1999). In relation to therapy it is “necessary that the client have intelligence above the borderline level” and for therapy to be successful there must not be too heavy a weight of adverse social factors (Rogers, 1940/1992, p. 163). Socio-economic factors thus cause in-equality in palliative care as in other areas.

An issue that might be considered a question of equality is the traditional expectation on gender, that implies that most lay palliative caregivers are women, typically the spouse of the patient followed by daughters. Women have traditionally been the nurturers and carers because they are regarded as natural carers (Brazil et al., 2005a, 2005b). Women face “enormous normative pressure to care for an ill family member” (Brazil et al., 2005a, p. 76). In our case three women formed a lay care giving troika, the son’s wife, mother and mother-in-law. The son’s father made substantial input in practical matters inside and outside the home. This division of labour was never discussed, just carried out, due to previously established patterns. A pattern of parents taking on different roles in caring for dying children was also recognized in a study on fathers’ and siblings’ roles in families with children in home hospice care (Lehna, 2001). The fathers were the main wage earners, technical caregivers, significant sibling caregivers and often “watched over the healthcare personnel or asked for assistance on behalf of their children” (Lehna, 2001, p. 20), while the mothers carried out the practical and emotional aspects of everyday care.

There is a risk that the complexity of the health system might imply that knowledge or relevant services is not available to the seriously ill patient and
their family caregivers at the time most needed (Burns et al., 2004). The equal
distribution of care can be an issue for the professionals. Much support
appears “to be available only to caregivers with insider information or a
terrier-like persistence” (Grbich, Parker & Maddocks, 2001, p. 31). “… the
rigorous case ascertainment approach, using population frames and epidemi-
ological methods to identify higher risk groups would help social workers to
identify families in need…” (Burns et al., 2004, p. 501). In our case the
palliative home care team provided the family with a network of services.
Often the family members did not even have to articulate their needs during
the care of the son. They may have implicitly showed them, as they were ar-
ticulate and well educated. Anyhow, it was not, according to the mother’s
experiences, a problem for the son to get the palliative care he needed or to get
support for the family members. Yet another factor that must be taken into
consideration is that the family members were healthy during the palliative
home care, a prerequisite to be able to take part in it (Brazil, Bedard &
Willison, 2002). Many elderly people wanting to care for a family member at
home are due to lack of physical strength probably not able to do so, and
dying at home is less likely for those whose family caregivers have poor health
(Brazil et al., 2005b).

In a theological model of everyday ethical problems in dementia care, four
ethical constraints were considered: self-determination, fairness, relevant
evidence-based knowledge and the nurses’ good life. The care provided
“should be fair in relation to others involved”. A “principle of equality, where
resources are distributed according to need”, implying that “the care is fair if a
greater good-life need is prioritized before a lesser need”, should guide the
Palliative care has been accused of being an exclusive care directed only to a
few patients, mostly cancer patients (Raunkiær, 2007). While caring for her
son the thought that other patients might have an equally or even greater need
than her son never occurred to the mother. The mother’s everyday life
concentrated on her son. Moreover, the nurses never gave her the impression
that her son’s care was at the cost of other patients. Nor did she think of the
ethical dilemmas related to a fair distribution of care that the nurses were per-
haps facing. The mother just wanted her son to receive the very best care all
the time. Retrospectively however, when reading about palliative care in the
research literature and talking to people who had been involved in such a care,
she realized that her son, herself and her family were privileged.
Concepts that can be related to the “institutionalized empathy” that benefited the mother will be summarized below. The focus is on the possibilities that institutions in the welfare state provide and not on the professionals carrying out the services.

The mother experienced the atmosphere at the ward where her son had surgery as flexible and permissive. This can be exemplified by the fact that the mother was allowed, for a period of some weeks on her son’s request, to sleep overnight on the ward. Flexibility was also shown when it was arranged for the son to have palliative daytime care at home, while he was still registered and spending his nights at the university hospital. Thus his care settings were for some time minimalized; the ward at night and his home during the day. Too many care settings can be a problem in palliative care (Burge et al., 2005). The arrangement was in agreement with the difficulties of making a definite separation between cure and palliation. However, if not made there is a risk that palliative needs are sacrificed for the hope of a cure (de Graves & Aranda, 2005). The special arrangement had substantial value to the son, mostly because he could spend time together with his daughter. To benefit the patient the hospital system and the palliative home care team pushed the degrees of freedom within the institutional rules to their limits.

Yet another example of using the system flexibly is the support given to the son, his wife and in turn their daughter from the resource team connected to the university hospital. This team was originally designated to support dying children and their families. Even so, the team agreed to meet the son and his wife once while the son was still at the hospital. They also met the wife on her own at a later date before the son died, to support her in preparing their daughter for her father’s impending death. It has been shown that in families, where the parents were unaware of children’s fears of death, children had more behaviour problems in comparison with children whose parents were informed (Silverman, 2000). In our case the son’s wife was informed by the resource team at the hospital as well as by her self-education. The wife was recommended books to read to her daughter, e.g. “Dödenboken” (“The Book about death”, Stalfelt, 1999). Of course all the support to the son’s core family was also supportive to the mother.

After the son left the hospital, the surgeon who had the main responsibility for the son at the ward invited the mother to see him whenever she felt the need. The mother met the surgeon some weeks after her son’s death. He explained to her about leiomyosarcoma. He reassured her that her son’s illness had been
beyond medical treatment even if it had been diagnosed earlier. This was a fragment of information that the mother could use in her grief work. Even the mother's family doctor provided her, over and over again, with information about her son's illness. He helped the mother read her son's medical journals to further reassure her that he had received the best possible treatment. To the mother it was important that this “institutionalized empathy” was accessible when needed. The demand for increased accessibility to primary health care is an ongoing discussion in Sweden (cf. Socialstyrelsen, 2004).

*Flexibility* is one of the words that also characterizes the actions undertaken by the palliative home care team. The nurses came on request, even if some visits were planned in advance, due to the son’s medication. If some of the family carers needed information between visits, there was always somebody to talk to on the phone. Each family member knew that if the team was needed they would come 24 hours a day.

*Continuity*, in the sense that the same professionals were available to the mother, was valuable. The mother did not have to repeat her predicaments when meeting representatives of the different institutions. The surgeon, whom she had learnt to know during her son’s illness, the social security official with whom the mother negotiated her sick leave (see below), and her long standing family doctor were all guarantees for continuity in the support.

A factor that facilitates or even makes possible for family caregivers to take part in home palliative care is financial *contribution* from the welfare system. The social security system incorporates an insurance that makes it possible to receive economic compensation for loss of earnings while caring for a dying relative or friend. A cost-benefit-analysis is hard to conduct in relation to the economic contribution. Taking into consideration that an important base for a reconciliation process can be developed during palliative home care, structures making it possible to care for a dying relative or friend at home seem to be profound, even if an economic cost-benefit analysis does not show the exact value of it money wise. It is possible that this base might contribute to an early return to work after a loss. Following the loss, the mother’s work as a civil servant entitled her to economic compensation for being off work for ten workdays. During this time, many practical issues had to be attended to and the family had time to support each other in different ways.

Important for the mother’s grief and bereavement was *time*. She was on full sick-leave for a couple of months and partially for a few more months. She was
allowed to do some work during her full-time sick leave, as long as she recorded and reported her working hours so that the economic contribution from the welfare system could be subsequently adjusted. The flexible use of the strictly regulated system was crucial to the mother’s readjustment to her professional life. Her family doctor supported the arrangement. A key concept in the arrangement was free choice underpinned by respect for and trust in the individual. It may seem that such an arrangement would be costly. However “The total cost of these unmet needs from human suffering, chronic health problems, and economic losses is incalculable” (Muller & Thompson, 2003, p. 199). One can wonder if not letting the mother work when she was able would have been more expensive. Allowing the mother to avoid the pressure of delivering a fixed amount of work was a relief to her. Not to work at all would expel the mother from making use of her professional knowledge; an aspect of her life that she felt must be reactivated after her loss.

The context of a workplace can be thought of as a place for a continuum of relations, from highly work oriented to warm and friendly. Work oriented relationships are institutionalized, that is the relationships are regulated in institutional rules and carried out within a framework of ascribed roles. One example of an institutional aspect of empathy is the way of organizing for the mother to come back to work after her break down. This process was arranged in a flexible and individualized way, implying that the mother was allowed to come back according to her own assessment of her abilities but within the rules of the institution. Thus the flexibility in the social insurance system was accompanied by a flexibility at her workplace giving the mother customized support.

In Figure 10 the characteristics of institutionalized empathy are summarized.

<table>
<thead>
<tr>
<th>Empathy based on institutions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access</td>
</tr>
<tr>
<td>Information</td>
</tr>
<tr>
<td>Continuity</td>
</tr>
<tr>
<td>Flexibility</td>
</tr>
<tr>
<td>Free choice</td>
</tr>
<tr>
<td>Economic contribution</td>
</tr>
</tbody>
</table>

Figure 10. Characteristics of empathy based on institutions
The institutionalized empathy as exemplified above is a “tangible, concrete and
general impersonal dimension” (Stoltz, 2006, p. 53) of support to palliative lay
caregivers and bereaved and built into the welfare system in Sweden. However,
an intangible dimension must also be included in the support to lay caregivers in
palliative home care and to the bereft. Such a dimension is referred to in this
study as compassion.

**Empathy based on compassion**

Even if the mother’s workplace was an institution where empathy could be
shown to her, the mother felt stigmatized when coming back to work after her
son’s death. The stigmatization was experienced by the mother when
colleagues turned their faces away when meeting her or were friendly in a way
that she had not experienced from them before. The mother felt as if she was
no longer seen foremost as a colleague but as a mother who had lost her son.
Some colleagues seemed to have forgotten that she was also a professional.
Some of them wept when seeing her. At those moments the mother had no
comfort to give, nor was she comforted by words like: “I understand what you
are going through.” Such words were not credible to her, albeit the person had
lost a child too.

Experiences of stigma are well recognized in research on grief and bereave-
ment. In the Tampa Bereavement Study (Sanders, 1992) a number of people
told about isolation after a loss. “As long as death is viewed by our culture as a
failure, we, the survivors, will experience some degree of shame” (Sanders,

Some of the mother’s friends, also colleagues and professionals in behavioural
sciences, helped her, by sharing their knowledge, thus activating her own, that
to a certain extent seemed to have faded away during the year of her son’s
illness. To these friends the mother could repeatedly talk about what she had
experienced during her son’s trajectory to death. They just listened respectfully,
and did not claim a common understanding, realizing that they could not share
her experiences. However, they tried to identify with her, drawing upon their
own experiences of being mothers.

The word compassionate connotes to shared emotions, or to refer to Lawrence
et al. (2006), that there is an overlap or shared representation of experiences
between persons. The volunteers working at hospices often do so as a result of
their own experiences. They often feel valued and find the work satisfactory.
A prerequisite for compassion is recognition, acknowledgement and trust. Had the nurses tried to persuade the mother to remain hopeful during her son’s final stage of illness, the mother would not have been able to trust them even in other matters. The respect, that lies in recognizing and acknowledging the mother’s hopelessness in regard to her son’s illness, built a foundation for further cooperation in the son’s care. Trust as credibility is another prerequisite for compassion to be valuable and significant. As mentioned before, those who claimed an understanding of what it is to grieve a child, without having experienced it, were not trustworthy to the mother. The compassion on the other hand from the nurses in the team was based in recognition and trust. The nurses had established a relation to the son and his family, and they knew of the “unfulfilled patient goals, and feelings of powerlessness” in relation to the cancer (Lally, 2005, p. 4).

The above mentioned should not be taken for an establishing of friendships. Rather the nurses in the team, including the physician, were professionals who showed their professionalism in a humane way. The mother relied on them to give her son the best care possible, and she was supported by their compassion as she felt that it was founded in their own experiences of the son’s trajectory to death and in their experiences of caring for dying patients.

“... each family is unique, as is each family member” (Andrews & Hood, 2003, p. 20). During the palliative care the family members were treated by the nurses and the physician in the palliative home care team not only as a group of people but also as individuals. It called for a profound professional experience and humanity to be able to code-switch in a flexible way in the tense situation and time. This is not always the case according to the research literature on palliative care, as mentioned before. The care of each of the individuals in the family was shown not only in verbal communication but also in actions. Yet another way in which care for the individual family members was experienced was by things. The rebuilt mattress communicated that the son and his wife were a married couple enjoying physical contact, the equipment box to their daughter that she was important in the care of her father, the black carrier that the palliative team was accessible, even if not in the home.
Flexibility included an openness for different kinds of questions and needs from the individual family member. Of course there must have been limitations, but to the mother it seemed as if all possible help needed was not only provided but also there when requested. This flexibility also strengthened the feelings of recognition of the family members’ individual capacities that were prerequisites for empowering them in the ongoing process to maintain and develop family caregiver’s engagement in the care.

Compassion supposedly also made the nurses aware of the mother’s need for bereavement support. The support services from the palliative care unit at the university hospital to which the palliative home care team was connected, was made available to the mother. Unlike hospital staff, who can be touched by the death of a child and report grief feelings and feel insecurity in supporting the family (Kaunonen et al., 2000), the palliative home care team transplanted their professional experiences into supporting the family immediately after the death of the son. They were “the key” to support (Melliar-Smith, 2002, p. 286) and made outreach.

Even the therapist recommended to the mother by her family doctor, showed compassion. The therapist’s compassion was shown in a respectful way, using the mother’s abilities and wishes to take part in planning the sessions. Indeed, the therapy was person-centred. This type of therapy is hard to evaluate. “Within academic and professional circles, the person-oriented approach is sometimes dismissed as facile or superficial” (Green, 2006, p. 300). One reason might be the difficulty in identifying the way in which the counsellor helps her client because the methods used in the therapy are transparent (Green, 2006). Research in the area of grief and bereavement has a manifold of obstacles to overcome, as was discussed in a previous chapter.

Parents in a parent bereavement group can be regarded as compassionate friends. In the USA the lay organisation “Compassionate friend” mainly consists of bereaved persons supporting each other. Unfortunately there was no such bereavement group in the mother’s home town. The mother had to drive 120 kilometres to join the group for a couple of hours. The meetings were worth every kilometre to the mother. The bereaved parent group was a forum in which the bereaved parents shared the experience of losing a child. Hence, they did not have to explain to each other. In the group the compassion, based on the shared experience of the loss of a child nurtured the mother’s reconciliation process.
Concepts related to empathy based on compassion are summarized in Figure 11.

**Figure 11. Concepts related to empathy based on compassion**

<table>
<thead>
<tr>
<th>Empathy based on compassion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recognition</td>
</tr>
<tr>
<td>Acknowledgment</td>
</tr>
<tr>
<td>Trust</td>
</tr>
<tr>
<td>Individualization</td>
</tr>
<tr>
<td>Empowerment</td>
</tr>
<tr>
<td>Outreach</td>
</tr>
<tr>
<td>Respect</td>
</tr>
<tr>
<td>Shared experiences</td>
</tr>
</tbody>
</table>

**Empathy based on shared loss**

The expression “shared loss” is used to indicate that to those who had learnt to know the son his death was a loss. They could *share the experience of losing* him to a certain degree. This does by no means imply that they experienced their loss in the same way. A wife losing her husband, a child her father, a mother her son, a sister and brother a brother, a friend losing a friend—are all different experiences according to their roles. The specific relationship between the survivor and the diseased influences experiences of loss. What they all shared was that the son, as a unique person (as we all are) was not alive anymore. Due to their earlier knowledge of the son, his friends mostly from school and basketball could and did help out in practical matters during his illness, e.g. transportation, finding just the right kind of soft drinks that the son liked, getting newly baked breakfast buns, choosing the right type of video films for him to watch, and doing things that it was difficult for the family members to find time to do. Such help is often very supportive (Falk & Lönnroth, 1999). They all saw his deterioration and they shared a loss when he died. They wept openly, men and women, thus contradicting the stereotypes of men not sharing pains, not grieving openly and avoiding strong, dependent and warm feelings (Walton, Coyle & Lyons, 2004). Outside her family the mother could share her loss with friends who had come to know her son. Empathy between persons who shared the loss of her son was self-evident. A glimpse of an eye, a hand to hold, a hug, even silence together with those who share loss can be supportive. There is no need to talk about the loss, as it is shared. No explanations are needed. Tears are accepted without comments.
The shared loss between the family members was a self-evident source of mutual empathy between the adults in the family. A very specific empathy based on shared loss is the empathy the mother felt from her granddaughter, when she recognized her grandmother as a bereaved parent. This empathy was interpreted by the mother as a sign of confirming the family bonds between her and her granddaughter and was highly significant to the mother.

The family members also shared the experience of the son’s palliative home care. They were there when he died. They all promised to do their utmost to help each other and the son’s daughter in times to come. In the pure literature there are many stories about promises on death beds. Sometimes they seem pathetic. There was nothing of the kind during the last days and hours of the son’s life. The promises came quite naturally, as the choice from the middle generation to be God-fathers and God-mothers to each others children had been previously made.

In the literature on grief and bereavement after the loss of a child there are some indications that siblings to the dead child and grandchildren have a great impact on the parents’ future lives (Dean et al., 2005). Parents who lose a child are often thought of as being more protective to surviving siblings (Rosenblatt, 2000), and to “form strong attachments to surviving siblings and to subsequent children” after the loss of a child (McLaren, 1998, pp. 283–284). This might be the case if the children are still members of the same core family. In our case however, the family’s already established bonds contributed to the palliative care. The fact that there were many family members standing by to take part in the palliative care implied that there were opportunities to take turns and to have breaks in the care that were necessary due to devastation, tiredness, work, etc. The mother felt that the bond between the family members strengthened and deepened during her son’s illness.

The mother’s protection was more directed to her granddaughter, who lost her father, than to her own children, whose roles in the family expanded. The father’s brother, the granddaughter’s uncle, was the one who threw his niece high up in the sky, when her father could not do it any more, her aunt together with the son’s wife saw to it that the cousins met on a regular basis. The children in the family were often a source of laughter, and thus supported the older family members.

When you can help even one person smile or learn to laugh again, it is the greatest gift you can ever give. (Gibson, 2004, p. 447.)
What made a positive difference to the mother is summarized in Figure 12.

**Figure 12. Empathy to the mother from different sources**

<table>
<thead>
<tr>
<th>Empathy based on institutions</th>
<th>Empathy based on compassion</th>
<th>Empathy based on shared loss</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access</td>
<td>Recognition</td>
<td>Personal knowledge of the deceased</td>
</tr>
<tr>
<td>Information</td>
<td>Acknowledgment</td>
<td>Family bonds</td>
</tr>
<tr>
<td>Continuity</td>
<td>Trust</td>
<td></td>
</tr>
<tr>
<td>Flexibility</td>
<td>Individualization</td>
<td></td>
</tr>
<tr>
<td>Free choice</td>
<td>Empowerment</td>
<td></td>
</tr>
<tr>
<td>Economic contribution</td>
<td>Outreach</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Respect</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Shared experiences</td>
<td></td>
</tr>
</tbody>
</table>

**Empathy to self**

In the Tampa Study on grief the participants unequivocally answered that family and friends gave the most support (Sanders, 1992). On the other hand “when family members appear to speak or grieve as one, it may be useful to question whether their apparent unity masks a diversity of feelings and needs” (Rosenblatt, 1993, p. 107). In the family in our case the members acknowledged that added to the shared loss was also a dimension of a private loss for each of them.

Even if there is a substantial value in sharing experiences of loss, there is still a dimension where a loss is highly personal and private (Schoka Traylor et al., 2003, p. 576). Nobody could ever weep a mother’s tears—dry them, but not weep them. The mother’s private grief is based in the biological bond between herself and her son and in the relationship between them. The quality of the emotional attachment to the diseased impacts the grief (Muller & Thompson, 2003). Even if there are similarities in mother–son-relationships in general—each is special. The specificity is encapsulated in memories that are not accessible for sharing. Each mother–child relationship is constructed from two personalities and their experiences of each other and cannot fully be explained.

Attempts have been made to describe grief in categories. In a study on whether persons with religious faith cope better with crisis than those without, four categories of grief were used; boundless, spontaneous, emerging, and suppressed grief. However, it was shown that the “sense of coherence” (Antonovsky, 1979) including meaningfulness, comprehensibility and manage-
ability that coincides with a view of life that is well integrated was not associated to any specific doctrine, be it an ideology, political or social opinion. Besides, there is a clear association between personality and the way of mourning (Kallenberg & Söderfeldt, 1992). This would imply that loss also has a private dimension. Private loss cannot be shared but ought to be respected.

To claim that personal grief is supported by empathy emanating from self may seem awkward. For the mother to acknowledge herself as a bereaved mother and to allow herself to grieve in whatever way and for however long she needed was probably in itself supportive to her. To allow herself to stop writing or reading for a while and let herself be overwhelmed by sorrow was a way to integrate the experience of having lost her son into herself and to construct a new self, that included her being a mother who had lost a child and was yet a researcher. To some extent such a process might be called self-empathic, not to be intermixed with taking on self-pity. The mother’s attitudes towards self became successively more caring and accepting, more empathic and understanding, more real and congruent. It is a matter of learning to be selfish and to be very gentle and patient with yourself (Sanders, 1992).

**Summing up**

Empathy on different levels supported the mother during the palliative care of her son and during three years of grief and bereavement. During the palliative care empathy based on the welfare system, providing flexible structures in which the mother was recognized and acknowledged, felt trust, was looked upon as an individual, was empowered and finally was reached by support after her loss, was of substantial importance to her. In her grief and bereavement compassion, shared experiences, shared loss, and strengthened family bonds supported her. Empathy to self allowed her to make use of all the support she received and was a part of her reconcilation process, that will be discussed in the next section. The levels of empathy are illustrated in Figure 13.
Finally the mother’s process of reconciliation will be summarized and related to the experiences of communication that made a difference to the mother—the empathy shown to her.

*Figure 13. Levels of empathy*
RECONCILIATION

The ultimate goal for support of bereaved parents is said to be connected to the concepts of meaning and meaning reconstruction. These concepts are however seldom discussed in a way “that accredits its complexity, its social character, and the conditions that facilitate or impede it” (Neimeyer, 2000, p. 555). Most contemporary research acknowledges the different connotations in the questions: What circumstances were involved in the child’s death? and How can parents find meaning in their lives after the death of a child? Answers to the first question can help parents find cognitive mastery (Wheeler, 2001), meaning-as-comprehensibility or sense-making (Murphy, Johnson & Lohan, 2003). Answers to the second question can contribute to the bereaved parents’ endeavours to find a purpose in life, “when previous goals and purpose have been challenged by a traumatic life event” (Wheeler, 2001 p. 52) or to find meaning-as-significance in their lives after the loss (Murphy, Johnson & Lohan, 2003).

The grieving process is often described as a stepwise progression to reconciliation. As mentioned before, a theory on the stages in such a process was presented by Sanders (1992). The first phase is shock, followed by awareness of loss, in which grief is both raw and painful. In a third phase, conservation–withdrawal, pain is more chronic than acute. The outcome of this phase has three scenarios; some may consciously or unconsciously seek their own death, others choose to live their remaining lives in “a diminished state of chronic grief”, and finally others make a “conscious decision to move forward—to move on and adjust to their loss”. The third group of persons experience “healing—the turning point” and move to a fifth phase, renewal. “Most importantly though, Sanders was one of the first theorists to affirm that individuals had choices within grief” (Doka, 2005–2006, pp. 145–146). Yet a sixth phase is added to Sanders’ phases, namely fulfilment. “At this point the grieving person could look back on his or her own life in a way that integrates
the earlier loss into the fabric of that own life” (Doka, 2005–2006, p. 148). It is important to acknowledge that one never rises above the loss, rather the loss becomes a major component in one’s life after the loss (Doka, 2005–2006). In the forthcoming the word reconciliation will be used when referring to this sixth step.

The mother’s grief process during her first three years of grief incurred that she had to reconsider and scrutinize many of the things in life she enjoyed before her son died. She did not completely transform her way of thinking and being, as many bereaved parents do not (Murphy, Johnson & Lohan, 2003) but reordered her priorities in life. It has been shown that bereaved parents keep their worldviews and attitudes prior to the loss but clearly change in value structure (Rubin, 1993). A Freudian perspective suggests that energy that was earlier invested in the relation to the child is invested in other family members and friends. A mother’s love, is in a way transformed into love for others; a brother’s or sister’s love (Fromm, 1977), a transformation that contributes to the resolution of grief (Dunne, 2004). According to Erikson a life crisis “is at the core of growth and development over the life span” (Balk, 2004, p. 367). In Erikson’s theory on human development the crises are formulated in eight dilemmas that are to be solved, basic trust versus basic mistrust, autonomy versus shame and doubt, initiative versus guilt, industry versus inferiority, identity versus role confusion, intimacy versus isolation, generativity versus stagnation, and finally ego integrity versus despair (Erikson, 1964/1995). The research literature repeatedly tells us that bereavement can foster human growth, i.e. is “mixed with loss and gain, mixed with an enduring sadness and a new appreciation for life and other persons”, that it “fundamentally challenges our very humanity” (Balk, 2004, p. 370). Perhaps the mother has improved in “emotion regulation” and grown as a person (Znoj & Keller, 2002, p. 561) in the sense that everyday calamities of life do not upset her anymore to the same extent as they did before she lost her son.

The word reconciliation is used for a state in which bereaved persons have integrated a loss into their lives and are still able to live a good life—a state when the reality of life without the loved one is accepted and when the bereaved can re-involve in the activities of living (Cohen & Mannarino, 2004). There are many ways of expressing such a state: “coming to terms with the loss” (Handsley, 2001, p. 26), “when the dead child is not forgotten but is no longer the central focus of their [the parents’] being” (McLaren, 1998, p. 285). “Redefining and reintegrating oneself into life”, “bereavement resolution”
(Balk, 2004, p. 368) and “epilogue to bereavement” (Rubin, 1993, p. 294) are others. Yet another way to describe the reconciliation process is

... writing the loss into one's life story by doing a variety of adaptive behaviors. (Muller & Thompson, 2003, p. 201.)

Like most parents (McLaren, 1998) the mother tried to make sense of what had happened to her and to her son. She did not seek meaning-as-significance (Murphy, Johnson & Lohan, 2003) or benefit-finding (Neimeyer, 2000, p. 551). She found “No meaning, just loss”, as one of the parents in a study on parents' meaning seeking after losing a child (Murphy, Johnson & Lohan, 2003, p. 396). The fact that some parents in that study found their lives meaningful also after their child's death did not imply that the death of their child contributed to the meaning, rather that they despite the death of their child could live a meaningful life. They were reconciled with their child's death and could go on living meaningful lives.

To the mother a meaningful life after her son's death implied precisely that; she could enjoy life despite the loss of her son. The expression “meaning reconstruction” (Neimeyer & Gamino, 2003, p. 851) as a central response to loss, is coherent with the expression “reconciliation”, that is not a process of accepting the death, but a process of adjusting to realities. How the mother's life developed, was a matter of her drawing on the good things in life that she could still enjoy. To learn to recognize these things was a part of her grief process.

The contexts in which the mother was supported in her grief, i.e. her family, friends, work, traditions, society etc., are also the contexts in which she found a meaningful life. The process of reconciliation and of finding meaning in life is highly individual as is the judgement about the quality of one's life on the whole. The private loss and her ability to give herself empathy are therefore factors that influenced her reconciliation process.

During her first year of grief her social counsellor told her, on her question about the time scope of the grief process, a question that many bereaved persons ask (Sanders, 1992), that she would know when she had come to terms with her grief. She would feel it in her belly. This not very scientific description of the outcome of a reconciliation process was first understood by the mother some years after the loss. There was a place within her where she kept her private loss. Sometimes the borders round the place fell down, but most of the
time it was encapsulated in her and in her ongoing life for some years after her loss. Her grief was not suppressed but given a space within her.

This experience of having the personal grief encapsulated in her belly implied that she could handle it. To some extent it was a matter of sorting things out. She realized that she could not weep her son’s tears for not being there for his family, for not seeing his daughter taking her first swim in deep water, for not taking her to her first school day, for not being there to walk her up the aisle, when she was to be married. All the things that her son would not experience were initially a huge source of sorrow for the mother. In the initial stages of her paternal grief, thinking of the joyful moments that her son would not experience caused the mother deep sorrow and were rationalized cognitively by her thinking: “It is my sorrow. I can not weep his tears. He is dead.” She had to persuade herself repeatedly. The fantasies of her son’s sorrow were gradually replaced by her own. She realized, that what made her sad was that she herself could not be there to experience those happy moments together with her son and that she would not see her son’s joy. As time went by her own sadness was not overcome, but seen in the light of all the positive experiences she could still have together with her grandchildren, children, friends, an interesting work, the beauty of nature—all the things she had enjoyed before her son died and that she could still enjoy. It was a matter of understanding and relating her sorrow to the right source. Her son was dead and could no longer feel sorrow. Her son’s despair, devastation and sorrow had to be handled as memories, whereas her own sorrow was to be wept.

Questions have been raised about whether the overarching framework of attachment theory is an adequate framework for explaining parental grief. According to attachment theory the child by proximity seeks protection by the caregiver, a safe haven, from which to discover the world. However, in the caregiving system also the caregiver’s concern to provide care is included. (Field, Gao & Paderna, 2005.) To be able to let go of these caregiving concerns is a matter of adjusting to the death of a child. “The degree to which the caregiving system is activated by the death of a loved one is likely to have direct bearing on the types of continuing bonds with the deceased” (Field, Gao & Paderna, 2005, p. 291). To start with the mother felt guilt for “letting her son dye”, though she knew cognitively that she could do nothing to prevent his death. The continued bonds between her and her son were initially expressed, among other ways, by the mother “weeping his tears”. Gradually the bonds between her and her son transgressed to memories of him. To the mother it
was a turning point in her grief to realize that the instinct to care for her son had survived her son.

Episodes of crises afford an opportunity for human growth and development, as mentioned before. In existential terms it allows persons to take responsibility for their actions and to experience a shift from “inauthentic” to the “authentic” (Jones, 1998, p. 58). Existential counselling has been described as an examination at a deeper level, where the individuals scrutinize the life-enabling and life-disabling effects of their self- and world-construct systems. In the process personal emptiness is transcended and the individual discovers how he or she can and must freely choose among the values that are life’s building blocks (Miars, 2002). Existentialism can be seen to be concerned with the search for existential authenticity, which refers to “autonomous self-creation of who and what individuals are to become” (Miars, 2002, p. 221).

Even if the mother was supported in her reconciliation process by a wide variety of interventions, her reconciliation process was and is still dealt with internally. The support arranged for her to have situations of comfort contributed to her internal development. The support might be thought of as scaffolding. However, as mentioned before, like teaching is parasitic on learning, support in grief is parasitic on the griever’s reconciliation. The reconciliation is an internal process based in personal grief; and an ability to give oneself empathy. The grief process leading to reconciliation can from a constructionistic point of view be an “intersubjective meaning-making process, that is accomplished by constructing narratives” (Klass & Goss, 2003, p. 789). Each individual narrative is nested in family, community, sub culture and cultural meta-narratives (Klass & Goss, 2003), i.e. the contexts in which the narrative is located.

From the discussion above the conclusion that the mother’s reconciliation process is once and for all accomplished should not be drawn. Parental grief is said to be lifelong and the reconciliation process an ongoing challenge (Sanders, 1992). What is important and surprising though is that a mother who lost a child might still have a good life if she allows herself the free choice to look for and enjoy the good qualities that life brings, a way of showing herself empathy. An expression from a bereaved wife, who suddenly lost her husband, describes herself three years after her loss (Hollander, 2004, p. 202):

“I am terribly damaged, and yet I am perfectly whole.”
Even if the mother about three years after her son’s death had a good quality of life, she will supposedly always have to add: “... considering the circumstances”. The death of her son will probably always be a reference point for everything that she will experience in the future. It will give her a baseline of sorrow against which everything else can be measured. And to her understanding whatever she experiences in the future it will not go below this level.
DISCUSSION

What if you opened your newspaper in the morning and read that some scientists had discovered truth, objectivity, the right morale and that a committee was to be established to formulate standards for belief, knowledge and actions? Rorty asks (1991).

Surely the public reaction to this would not be: “Saved!” But rather: “Who on earth do these philosophers think they are?” It is one of the best things about the intellectual life we Western liberals lead that this would be our reaction. (Rorty, 1991, p. 44.)

This study does not claim to be objective, whatever definition we give to the concept. The writings that are used as data are not found, they are made, in a performance that mediate between experience and the text (Jones, 2005). Furthermore, they are made “through culturally shared narrative types, formats and genres” (Atkinson & Delamont, 2005, p. 825). Rather, the value of the study should be measured according to its ability to explain the pragmatic questions: What experiences of communication had a positive impact on a mother during lay caregiving in palliative home care of her adult son and in her grief and bereavement? and Why did these experiences of communication have a positive impact?, i.e. the questions formulated in the objectives for the study.

In the approach the data is described as autobiographic. Autoethnographic could have been chosen instead, as “autoethnography works to hold self and culture together, ... writes a world in a state of flux and movement—between story and context” (Jones, 2005, p. 764). This is also relevant in an autobiography in which one person’s life is in focus and not a group of persons’. “Many now argue that we can study only our own experiences. The researcher becomes the research object” (Denzin & Lincoln, 2005, p. 645). On the other
hand, there are also many researchers who claim that they objectively can study the experiences of others.

Describing and interpreting activities constitutes a large part of many case studies. As activities are influenced by contexts, the mother’s experiences have been located in social, cultural and situational contexts. The settings for the palliative home care, the family structure, and to some extent the family socioeconomic situation, the network made available to the patient and the family are described. In the interpretations of the mother’s personal belief the relationship to her son, to other family members in general, to her granddaughter specifically and to friends and colleagues have been revealed. In doing so some personal meanings of events and relationships are passed on and others are failed to be passed on. Similarly, “the readers, too, will add and subtract, invent and shape—reconstructing the knowledge in ways that leave it differently connected and more likely to be personally useful” (Stake, 2005, p. 455).

Even if meanings do not transfer intact but instead squeeze into the conceptual space of the reader, there is no less urgency for researchers to assure that their sense of situation, observation, reporting, and reading stay within some limits of correspondence. However accuracy is construed, researchers don’t want to be inaccurate, caught without confirmation. Counterintuitive though it may be, the author has some responsibility for the validity of the readers’ interpretations. (Stake, 2005, p. 453.)

Apart from describing the contexts, research in the field of palliative home care, grief and bereavement have been included in the interpretations. The study is thus embedded in a framework of theories, earlier research and different perspectives from which to scrutinize the findings.

In this final chapter some methodological issues on the use of narratives in research are raised before the findings from the narratives and the interpretations are summarized. The interpretations of the narratives will be seen as a whole, an overall story, from the mother’s experiences of her son’s cancer diagnosis to her feeling of empathy from her granddaughter, by then in her sixth year. The findings will be discussed according to its scientific contributions to the field of palliative home care and parental grief and bereavement.
The method

The study claims to search narrative knowledge, a knowledge that is maintained in emplotted stories. Each of the interpretations of the narratives can be seen as an outcome of a narrative analysis. Such an analysis starts with questions as “How did this happen?” or “Why did this come about?” and searches information, that can be included in answers to the questions. Such information reveals uniqueness of the individual case or system and provides an understanding of its idiosyncrasy and particular complexity (Polkinghorne, 1995). The relationships between the mother and other individuals and the significance of other persons’ support to the mother in her son’s palliative home care and her grief and bereavement are the main components of the story. Significant persons are then included in the story, according to the mother’s experiences. They are presented in the settings in which they made a positive difference to the mother. Some background variables about the mother are given according to her socio-economic status, her state of mind and physical condition in different phases of the four years that are included in the study.

Attention to the inner struggles, emotional states, and values of the protagonist provides important data in narrative analysis (Polkinghorne, 1995). In a study where the researched, the agent, is also the researcher this implies that the agent’s meanings and understandings not only concern the experienced events. Also in the interpretations the researcher’s understandings are unfolded. Furthermore it implies that understandings that are achieved in retrospect ought to be and are included in the story. However, not only what happened within the time scope of the study, but also prior events might influence the interpretations and should thus be accounted for (Polkinghorne, 1995). This is not fully accomplished in the study. For instance, the mother’s appreciation of having almost immediate access to primary care and seeing the same doctor for several years is probably influenced by earlier experiences of long waits for an appointment and of repeating information to different physicians in primary health care services. Instead of recalling this event a picture of in-accessibility in the primary care has been given. Yet another example is that the mother’s appreciation of the home palliative nurses’ profound professionalism and experience can be contrasted to other experiences of nurses, in whom the mother doubted that they had the experiences needed to care for her son. In short, all positive experiences are intuitively valued in relation to other experiences, more or less positive. A reason for not including earlier events into the interpretations to the extent that a criterion of a historical continuity
(Polkinghorne, 1995) is met, is that the story told is not a life story. This might be a limitation.

The configuration process of data into a story often starts with the story’s ending or dénouement (Polkinghorne, 1995). This is the case in the construction of the four narratives in this study. In the study the narratives are told almost chronically. In the first narrative the tense communication between the mother and her dying son due to her son’s hope and disavowal and the mother’s fear and despair was, according to her experiences, reverted to the communication style that she and her son had before he was ill. The dénouements in the other stories are that the family managed to be lay palliative caregivers to the son until he died, the mother’s way out of an acute phase of grief and finally the strengthened family bond, exemplified by the shared loss between the mother and her granddaughter, all according to the mother’s experiences. The overall questions that a story should answer are: How did all this come about? and What events and actions contributed? In the interpretations these questions were answered. Together the four interpretations shape an overall plot: From the diagnosis of an adult son with cancer and his death to the mother’s reconciliation, according to the mother’s experiences. This overall plot glues the four narratives and their interpretations together. Thus an overall question of: How and why did the mother reach reconciliation? has an overall answer: Through experiencing empathy from different sources in different contexts.

To the previously discussed words indicating validity of this kind of research Blumenfeld-Jones adds fidelity, “an obligation towards preserving the bonds between the teller and receiver by honouring the self-report of the teller and the obligation of the original teller to be as honest as possible in telling” (Blumenfeld-Jones, 1995. p. 28). Most often the judgement of fidelity depends on at least two persons, the teller and the listener, the researcher. Between these two parties there is a bond, a betweeness, that has two aspects; the bond between the original teller and the narrative inquirer and the interaction between the original teller and the context of the narrative. In this study there is only one person, but still two parties. The teller is a mother and the inquirer a researcher in the same person. In ordinary everyday life one person has more than one role. As a bereaved mother three years after her son’s death the mother went to work as before, carried out what was expected from her, that is to research and to tutor doctorate students. The fact that she was bereaved had of course changed her, but not to the extent that she was not asked to carry out or not able to research anymore.
However, in this study yet another bond is built, that can risk fidelity, namely the mother’s drive to construct a story that is beneficial to herself as a teller and not as a researcher. Even if the mother as a researcher is conscious about this risk, it cannot be eliminated. This is a limitation of the overall story in the study.

Would the risk have been eliminated had another researcher told the story? First, another researcher would not have told the same story. Secondly, another researcher would probably have integrated his or her own preconceptions of terminal illnesses, fear, sorrow, grief, bereavement etc. into the interpretations, thus constructing his or her own story.

The second bond concerns the relationship between the original teller, the mother, and the context of the story. “Even when the inquirer and the subject are one and the same person the issue of recoding would still exist” (Blumingfeld-Jones, 1995, p, 32). What is told in the overall story is a selection of experiences made by the mother over a four year period. The selection implies that the mother’s writings diminish her experiences and what is selected from the writings to be included in the narratives in turn is a further diminishing. The issue of selecting events to be included in the narratives is also a matter of making selections that makes the story credible to an audience. The story ought to have a resonance, based in a communality between an audience member’s life-experience. However, should audience members not feel resonance they could still find fidelity in the story through its contextualization. (Blumingfeld-Jones, 1995.)

**Summary of the findings**

A brief summary of the findings is given in Figure 14 to make a starting point for a discussion on what scientific contributions came out of the study.
Figure 14. Summary of the findings

Briefly the overall story captures four years of a mother’s experiences of communication that supported her from her son’s diagnosis with cancer to her reconciliation after his death. The mother experienced support in different contexts and from different sources. Empathy was chosen as a common denominator for her experiences of the support. In the following some issues, that to the author’s knowledge are not discussed or only touched upon in the literature of palliative care of an adult child and grief and bereavement after the loss, will be highlighted. Firstly, some notions on the concepts of death and dying will be addressed.

The concepts of death and dying
There seems to be an inconsistency in the use of the concepts of death and dying in the research literature on palliative care that also has implications regarding the concept of anticipatory grief.

<table>
<thead>
<tr>
<th>Narrative</th>
<th>Hope and disarowal versus fear and despair</th>
<th>Communication in action between family caregivers and a palliative home care team</th>
<th>Words that made a difference in grief and bereavement</th>
<th>Communication across generations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time</td>
<td>From the son’s diagnosis to his death</td>
<td>During the palliative care</td>
<td>During the mother’s first year of grief</td>
<td>From the son’s death until three years after</td>
</tr>
<tr>
<td>Empathy shown to the mother through</td>
<td>recognition</td>
<td>trust</td>
<td>information</td>
<td>breaks in the grief</td>
</tr>
<tr>
<td></td>
<td>acknowledgment</td>
<td>flexibility</td>
<td>control</td>
<td>memorizing rituals</td>
</tr>
<tr>
<td></td>
<td>respect</td>
<td>continuity</td>
<td>friendship</td>
<td>confirming family bonds</td>
</tr>
<tr>
<td></td>
<td></td>
<td>accessibility</td>
<td>shared experiences</td>
<td>shared loss</td>
</tr>
<tr>
<td>In the context of</td>
<td>hospital palliative home care</td>
<td>hospital palliative home care</td>
<td>hospital palliative home care</td>
<td>hospital palliative home care</td>
</tr>
<tr>
<td></td>
<td>primary health care</td>
<td>primary health care</td>
<td>primary healthcare</td>
<td>primary healthcare</td>
</tr>
<tr>
<td></td>
<td>friendship</td>
<td>friendship</td>
<td>social counselling</td>
<td>social counselling</td>
</tr>
<tr>
<td></td>
<td>family</td>
<td>friendship</td>
<td>psychotherapy</td>
<td>psychotherapy</td>
</tr>
<tr>
<td></td>
<td></td>
<td>friendship</td>
<td>social security</td>
<td>social security</td>
</tr>
<tr>
<td></td>
<td></td>
<td>family</td>
<td>parent bereavement group</td>
<td>parent bereavement group</td>
</tr>
<tr>
<td></td>
<td></td>
<td>self</td>
<td>friendships</td>
<td>friendships</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>family</td>
<td>family</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>self</td>
<td>self</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>grandmother-grandchild relationship</td>
<td></td>
</tr>
</tbody>
</table>
First, dying is hard to define. In a sense we are all dying as soon as we are born. In research literature on palliative care the concept of dying seems to be used when there is an approximate estimate of the time for death. In this study death is defined as the endpoint of the dying trajectory. Dying is then in the individual case dependent on who defines and uses it. In our case the mother’s perception of her son’s dying stretched over far longer time than her son’s. On an institutional level the medical professionals are those, who define when a patient is dying and entitled to palliative care.

In the research literature dying and death are often used synonymously, and expressions as “a dignified death” or “dignified dying” refer to the trajectory to death and not to the endpoint of it. The reasons for separating the concepts of death and dying are at least twofold. It is not possible to know how death is experienced from the patient’s point of view. Only those present when death occurs are able to describe it. However, the trajectory to death can sometimes be described by the dying patient. The knowledge of death is always second hand. The other reason is that death of a loved one starts the process of grief. As long as a person is alive there is still a hope to support his living. The mother was still mothering while her son was dying. This was put to an ultimate end when her son died. Even if his death was anticipated, and she had prepared herself for it for a reasonably long time, the change from being a caring mother to a bereaved mother was definite. It seems as if research on dying and death would benefit from making the demarcation between the two concepts more explicit.

A four year long case study
The mother’s experiences during four years are described and analyzed. In research on dying and bereavement the same individual is seldom followed through such a long time. One exception is the aforementioned study in which 17 persons were interviewed and followed up three years after their loss (Kallenberg & Söderfeldt, 1992; Kallenberg, 2005). As mentioned in the introduction research on the grief process often uses cohorts, implying that different individuals’ experiences are studied, e.g. one, two, and three years after the loss. The variance within individuals is thus embedded in the variance between groups, as the cohorts are independent, though studies on individual progress also should consider the individual characteristics. The cohort studies of course may provide a picture from a distance in an epidemiological way of speaking. A case study can complement the overall understanding of palliative home care, grief and bereavement from the family members’ point of view and take the individual variance over time into account.
Parents as home palliative lay caregivers to adult children

The knowledge on terminal ill adult children is sparse. There is hardly any research on the relationships between health care professionals and parents of a dying adult child (Dean et al., 2005). To understand the mother’s experiences of communication during her son’s palliative care theories from areas bordering the specific situation had to be used.

It is not unreasonable to believe that one prerequisite for parents caring physically for an adult child is that a relation of profound trust between the parent and the child has been established before the terminal illness. In our case the patient was a young man, allowing his mother to come back into his life in a way that she had not been for decades. However, the mother and the son never talked about him receiving care from his mother as an obstacle. To the mother it was a privilege. According to attachment theory from the caregiver’s perspective the mother’s experiences can be briefly described as: Once a mother—always a mother. The caring came natural to her and according to her experiences also to her son.

On the other hand the son, together with the palliative home care team, was in charge of his care. Even though the mother as a mother felt responsibilities to see to it that her child was as comfortable as he ever could be, it was up to him to articulate his needs. The mother also had to listen to her son’s wife, not imposing on the spouse’s own views of the son’s illness and impending death. In this “walking a tight-rope” the palliative home care made substantial efforts to keep the communication between the family members on a constructive level. The nurses and the physician in the team recognized and acknowledged the son’s hope and disavowal and the mother’s fear and despair, and supported each of them individually.

Customized support

The benefits for the patients in palliative care to have the care customized are repeatedly stressed in the research on palliative care. Furthermore, support to the soon to be bereaved family members who take part in palliative home care can already commence during the caring. To have been trusted, respected and empowered to care for her dying son was supportive to the mother when her son was dead. Research points to the association between supporting during caregiving and bereavement adaptation (Koop & Strang, 2003). The knowledge that she had done her utmost to help out during her son’s palliative care was one of the circumstances that comforted the mother in her grief.
Even if there is some inconsistency in the research on the grief process, the overall notions are that it is personal and individual. General models describing a stepwise progression are numerous, but also emphasize that individuals go through them in their own ways, using the time they need. Also relapses are natural. However, customized support to the bereaved families is, to the author’s knowledge, not frequently described in the literature. Instead, much of the discussion on support to the bereaved is about different psychotherapeutic techniques. The bereaved themselves are seldom viewed in a multivariate context. This study points to the importance that support to a grieving parent is not only an issue for the palliative care. For a bereaved parent to be able to come to terms with grief, the welfare system and its institutions ought to use their means flexibly.

Shared loss across generations
In research on grief and bereavement intergenerational aspects are seldom discussed. Often the family as a whole is said to give the most important support to bereaved parents. This study points to the support the mother as a grandmother experienced from a preschool aged granddaughter, who was also bereaved. Apart from concrete help in establishing rituals when visiting the grave and giving opportunities for positive remembrance, her granddaughter made the mother’s regressive behaviour something natural when they spent time together. The attachment between her son and his daughter was confirmed, to the mother’s comfort. The bond between herself and her granddaughter supported the mother. To use a metaphor it was like a bridge between generations over a dead father and son.

Whose tears?
Attachment theory adds much knowledge from the point of view of the care receiver. More seldom is attachment theory used to understand separation anxiety from the provider’s perspective. The ultimate stop for a mother to provide care for her child is the death of the child. Even if the son was dying the mother could still provide care, physically and emotionally. As long as he lived she was a care provider even though she could not protect her son from his illness.

When her son died her mothering for him was put to and end. To a great extent her thoughts and doings had been related to her son during a year. She was prepared for his death—and yet not. What research on grief repeatedly stresses is that you cannot imagine loss if you have not experienced it. This was also true for the mother. It took a long time and much effort for her to
separate her own sorrow from her imagination of her son’s sorrow. She had lived so close to his hope, disavowal and finally despair for so many months, that she still carried it within her. She had shared his sorrow for not being there for his daughter in the future, and for a long time after his death she wept his tears, as parents sometimes do on behalf of their children.

The expression to “relearn the world” (Attig, 1996) after a significant loss, very well captures the mother’s reconciliation process. The mechanisms underlying the process are still to be studied. As mentioned, attachment theory could serve as a starting point to be applied from the caregiver’s perspective as well.

Focus on communication that made a positive difference

As mentioned in the introduction research on palliative care often focuses on negative aspects concerning lay caregivers. Much research on grief and bereavement on the other hand ends up with recommendations on how to make support effective and how to make positive differences to the bereaved. This is especially the case in studies where the authors have personal experiences of counselling or of losing a significant person by death (e.g. Attig, 1996; Sanders, 1992).

The mother’s writings could have been data in a study that focused on the mother’s negative experiences of her son’s care before the palliative home care team was involved or on experiences of disrespectful treatment from professionals as well as from persons at large in her grief and bereavement. However, negative aspects have been touched upon through relating the mother’s experiences to research in different areas. The choice to tell why the mother had positive experiences of communication during a hard time was a means to give voice to a lay caregiver’s impressions of home palliative care, that might in turn support the professionals that devote their time to the dying and their families. They did make a difference.

Also the mother’s grieving process is studied based on positive experiences, i.e. what helped her in her bereavement, what worked. Though grief is personal and learning to live with a profound loss is an individual process some of the positive interventions might be of advantage even to other bereaved parents. For the mother as a researcher and an educationalist it is more fruitful to tell about what worked than what did not.
The focus on positive experiences does by no means imply that the story told is a happy-ending-story. A dénouement of the story is presented—but not the end. To grieve a child is a lifelong hardship to a parent.
SVENSK SAMMANFATTNING

Det svåraste en förälder kan ställas inför är att se på när hennes barn dör och att sörja barnet efteråt. Den övergripande frågan som ställs i denna avhandling är hur stöd kan ges till en mor som upplever detta svåra.

Avhandling handlar om vård i livets slutskede, palliativ vård, som bedrivs i patientens hem och om sorg. Forskning visar att många döende patienter väljer att dö hemma. Vård i hemmet av svårt sjuka patienter kan kräva stora vård insatser av såväl sjukvårdspersonal som anhöriga och vänner. Litteraturen kring denna typ av vård visar på de svårigheter som finns, när det gäller att forska om vård av döende patienter. De som vårdas är ofta alltför sjuka för att kunna intervjuas, vilket kan ha till följd att de som är svårast sjuka inte kommer till tals. De anhöriga till döende utgör en sårbar grupp, som det av etiska skäl kan vara svårt att vända sig till i forskningssammanhang. Därför saknas i stor utsträckning kunskap ur ett brukarperspektiv om vård i livets slutskede.


I den palliativa vården ingår stöd åt anhöriga. Särskilt viktigt är sådant stöd om de anhöriga är direkt involverade i vården. Även stöd till efterlämnade sörjande kan finnas som inslag.

Studien kan ses som ett komplement till forskningen om palliativ vård ur ett anhörigperspektiv. Författaren till avhandlingen är en mor, som deltog i vården av sin vuxne döende son i hans hem under överinseende av ett palliativt hem-sjukvårdsteam. I hans vård deltog också hans fru och svärmor. En treårig
dotter fanns i familjen. Även moderns sorg efter sonens död behandlas i avhandlingens.

Moderns upplevelser av positivt stöd i form kommunikation under sonens palliativa vård beskrivs och analyseras. Kommunikationen i det stöd modern fick under det första sorgeåret samt kommunikationen under en treårsperiod efter förlusten mellan henne och hennes sondotter, som förlorat sin far, studeras också utifrån moderns upplevelser.

Syftet med avhandlingen är att

• beskriva och analysera vilka upplevelser av kommunikationen i den palliativa hemsjukvården av en vuxen son och i moderns sorg som hade positiv betydelse för modern, och
• förstå varför kommunikationen upplevdes som positiv.

Fyra sammanhang i vilka kommunikationen utspelade sig beskrivs och analyseras, nämligen kommunikation

• mellan modern och hennes döende son under den palliativa hemsjukvården,
• mellan den vårdande familjen och det palliativa hemsjukvårdsteamet,
• i det stöd modern fick i under det första året av sorg, och
• mellan modern och hennes faderlösa sondotter.

**Ansats och metod**


Invändningar som kan resas mot angreppssättet är att det kan vara svårt att analysera egna upplevelser. Å andra sidan finns de som undrar om man överhuvudtaget kan analysera sådant man inte har erfarenhet av. Frågan om huruvida forskaren kan förhålla sig neutral till sina data och det aktuella fältet är naturligtvis giltig för all forskning och något speciellt angreppssätt som garanterar neutralitet går svärligen att finna. Snarare är det en fråga om ett
kontinuum av mer eller mindre hög grad av engagemang och involvering. Närhet – distans behöver inte vara en dikotomi, utan närhet och distans kan ses som lägen i ett kontinuum. En självstudie av det slag som denna avhandling präglas av närhet i de beskrivande delarna och rör sig mot distans i de analyserande. Neutralitet efterstälvas inte. Tvärtom har det ansetts vara en förtjänst att forskaren integrerar sin egen förståelse i tolkningen och analyser av de upplevelser som beskrivs.

Datinsamling

Från tidpunkten för beskedet om sonens cancerdiagnos till hans död förde modern dagbok. Sådant som var svårt att förstå och ännu svårare att tala om, nämligen att hennes son riskerade att dö, skräck och förtsjukvand inför detta, skrev hon om i dagboken. I den samlade hon de fasor och den förtsjukvand som hon i stunden inte kunde ta till sig eller bearbeta för att på något sätt skjuta upp bearbetningen till senare tillfälle. Inom sig kände hon att hon skulle komma att behöva reflektera över och bearbeta det hemska. Dagboken utgör en del av rådata i studien. Inte förrän ett år efter sonens död läste modern sina dagboksanteckningar.


För skriverierna gäller att de inte var ämnade att användas i en studie eller avhandling. De var fritt nedtecknade upplevelser, i dagboken i ett mycket kort tidsperspektiv, i de impressionistiska skriverierna i ett längre, vilket medför att de senare är mer elaborerade. Förutom skriverierna har andra anteckningar använts som stöd för minnet, t.ex. kalendrar, scheman och utdrag ur sonens journal.
Dataanalys
Skrivorna, rådata, har en narrativ karaktär. Begreppet narrativ är inte entydigt definierat i berättelseforskningen. Inte heller är vokabulären kring analys av narrativer eller narrativ analys entydig. För att beskriva det tillvägagångssätt som använts vid analysen av rådata, har begreppet *grader av narrativitet* använts (Paley & Eva, 2005). En skala av narrativitet kan beskrivas som i figuren nedan, där 1 är lägsta graden av narrativitet.

**Figur 15. Grader av narrativitet (Paley & Eva, 2005, s. 87, författarens översättning)**

Analysen av skriverierna syftar till att uppnå en allt högre grad av narrativitet, även om skalstegen inte fullständigt passar in på analysprocessen, som beskrivs nedan i fyra steg.

**Steg 1:** I skriverierna identifierades först händelser som relaterades till kommunikation mellan modern och hennes döende son, mellan sonens familj och det palliativa hemsjukvårdsämnet, i stödet till modern under det första året av sorg och mellan modern och hennes sondonen under tre år efter deras förlust. Kommunikation som var av positiv betydelse för modern arrangerades i tidsordning. Begrepp som hade förklaringsvärde avseende den positiva upplevelsen av kommunikationen identifierades. Den förförståelse och de erfarenheter modern som dels deltagare i den palliativa vården, dels forskare inom det beteendevetenskapliga området har med sig in i analysarbetet hade naturligtvis betydelse för vilka begrepp som identifierades. På denna punkt skiljer sig inte tillvägagångssättet från andra typer av innehållsanalys.

**Steg 2:** Fyra berättelser, narrativer, konstruerades, som illustrerade de fyra olika sammanhang som studeras och bärande begrepp i kommunikationen. Illustrativa händelser som beskrev positiva upplevelser av kommunikation valdes att
ingå i berättelserna. De fyra berättelserna översattes till engelska. Tämligen fylliga utdrag ur skriverierna ingår i dem.

Steg 3: Berättelserna tolkades i relation till teorier och forskning rörande palliativ vård och sorg samt sattes in i de kontexter i vilka de utspelats. Ett annat sätt att uttrycka detta steg är att berättelserna lokaliserades i teoretiska och kontextuella ramverk.

Steg 4: De fyra berättelserna rör ett tidsintervall om fyra år och utgör tillsammans en större berättelse som handlar om en moders positiva upplevelser av kommunikation inom palliativ hemsjukvård och i hennes sorg. Empati framstod som en gemensam närmare för de positiva upplevelserna av kommunikationen. Denna större berättelse tolkas i relation till ett samhälle som gömmer döden. En analys av hur modern integrerade sin förlust av sonen i sitt liv i ett sådant samhälle utgör en sista del av analysprocessen.

**Resultat**

De fyra berättelserna är resultatet av de första och andra stegen i analysen av data. Berättelserna summeras kortfattat och tolkningarna av dem, det tredje steget i analysen, sammanfattas under de rubriker som berättelserna fått. Det fjärde steget redovisas för sig under rubriken ”Empati i olika kontexter” och ”Förlusten—en del av livet”.

**Hopp och förnekelse kontra fasa och förtvivlan**


Inte förrän ett palliativt hemsjukvårdsteam involverades i vården fick modern en möjlighet att tala med sjukvårdspersonal om det som var hennes störstafasa, att hennes son skulle dö. Det palliativa teamet såg hennes fasasamtillvälv och medgav att hennes son skulle dö. Sjuksköterskorna och läkaren talade med modern på ett sätt som ingen gjort tidigare. Modern kände sig tagen på allvar.

När sköterskorna och läkaren i teamet förklarade effekterna och bieffekterna av cellgiftsbehandlingen på ett intellektuellt och icke påtvingande sätt för sonen insåg han, att han inte hade mycket tid kvar att leva och att denna tid skulle vara bättre utan cellgifter. Då, ungefär en vecka innan han dog, kunde han och hans mor dela djup bedrövelse. Deras kommunikation återgick till att vara öppen, varm och nära.

Sonens hopp och förnekelse och moderns fasasamtillvälv var betydelsefulla begrepp som bidrog till att förklara kommunikationen mellan sonen och modern under hans sjukdomsperiod. Stödet till modern från sjuksköterskorna och läkaren i det palliativa hemsjukvårdssteamet kan summeras i att de

- såg och bekräftade sonens hopp och förnekelse och moderns fasasamtillvälv samt
- respekterade sonens och moderns integritet.

**Kommunikation genom handling mellan vårdare i familjen och ett palliativt hemsjukvårdssteam**

I detta avsnitt gör sig modern till talesman för den vårdande familjen. Såväl verbal som icke-verbal kommunikation är aktuell.

Många sjuksköterskor deltog i den palliativa vården av sonen. Några av dem kom närmare familjen än andra. En av sjuksköterskorna hade huvudansvaret för sonen. En läkare ingick i vårdeamnet.

Familjen där döden var i nära antågande levde ett vardagsliv så långt det någonsin var möjligt. Sjuksköterskorna gjorde sig hemmastadda i familjen, respekterade och uppmuntrade familjen att leva som vanligt. Ett brett utbud av stöd ställdes till sonens och familjens förfogande genom teamets försorg; transporter till universitetssjukhus, medicin, en vårdplats på en onkologisk klinik att använda under kortare perioder, specialister inom olika medicinska områden, och slutligen den sista transporten av sonens kropp till bårhuset.

169
Även stöd, förmedlat av materiella ting tas upp. T.ex. visade den svarta lådan, placerad i familjens badrum, som innehöll utrustning för sköterskorna att använda i vården av sonen, att hjälp fanns tillgänglig, även om teamet för stunden inte var i hemmet. En önskan om att ett skohorn skulle finnas i hemmet för läkaren i teamet att använda vid sina besöck innebar för moder att läkaren skulle komma ofta. En ombyggd madrass visade att sonen och hans fru sågs som ett par som hade behov av och ville vara nära varandra. Tingen talade – även om avsikterna med tingen primärt var andra än vad de förmedlade.

Ett nyckelbegrepp i tolkningen av moderns upplevelser av kommunikationen under sonens palliativa vård är **tillit** mellan sonen och hans familj å ena sidan och det palliativa hemsjukvårdsteamet å andra. Tillit förefaller vara grunden för att familjemedlemmarna skulle kunna bidra till sonens vård och känna att de var betydelsefulla i den. Faktorer som bidrog till tilliten var **flexibilitet** och **kontinuitet**.

**Kommunikation som hade positiv betydelse i moderns sorg**

Några veckor efter sonens död befann sig modern i ett tillstånd av posttraumatisk stress, enligt hennes familjeläkare. Symptomen på denna kan summeras som skuldänslor, förvirring, fysiskt sammanbrott, ångest, sömnlöshet, förlust av kontroll, tvångsföreställningar och känslor av att vara stigmatiserad.


**Information**, samtal om kontroll, **vänkapp**, ett delat skratt och **gemensamma upplevelser** identifierades som betydelsefulla inslag i moderns sorgarbete. Stödet kom i första hand från människor i hennes närhet, familjemedlemmar och nära vänner. Vidare hade en grupp av andra föräldrar vars barn dött stor betydelse för moder. Med dessa föräldrar kunde hon dela upplevelsen av att vara en förälder som förlorat ett barn genom död. Det professionella stödet hon fick var i stor utsträckning sådant hon själv sökte. Häri ingick stöd från den läkare som opererat hennes son, hennes familjeläkare, kuratorn som var knuten till det palliativa hemsjukvårdsteamet, en psykolog och sist men inte
minst sjuksköterskorna i det palliativa teamet. I detta sammanhang var modern privilegierad, då hon kunde artikulera sina behov och visste var att söka stöd.

**Kommunikation över generationsgränser**

Från ett team som specialiserat sig på familjer i dödens vänturum, knutet till ett universitetssjukhus fick sonens fru råd om hur deras då treåriga dotter skulle kunna förberedas inför faderns död. Den lilla flickan visste att hennes pappa var mycket trött och mycket, mycket sjuk. En kvart innan han dog, sa hennes mamma till henne att säga ”ett fint adjö” till sin pappa ”för pappa kommer inte att vara här när du vaknar i morgon”. Det gjorde hans lilla flicka och tio minuter därefter dog maken, pappan, brodern, sonen med familjen omkring sig.

Under de kommande månaderna och åren tillbringade modern mycket tid tillsammans med sin sondotter. Genom henne upplevde modern (farmodern) en naiv sorg som gav tröst. I ett kort tidsperspektiv fick modern pauser i sorgen genom att delta i sondotterns fantasier om att hennes pappa sa att på en stjärna och såg hur de båda lekte tillsammans. Genom att barnbarnet önskade höra berättelser om sin far fick modern (farmodern) möjlighet att minnas glada stunder tillsammans med sonen och titta på foto av honom som frisk och levande. Genom barnen i familjen etablerades ritualer som kunde underlätta besöken vid sonens grav. I ett längre perspektiv blev modern tröstad av att uppleva hur hennes sondotter bekräftades av familjeband som finns mellan dem, och som modern tyckte sig se, bl.a. i att hennes roll som sörjande förälder bekräftades av sondottern, även om dessa upplevelser var moderns konstruktioner.

**Empati i olika kontexter**

En idealbild av vad som är en god död har under århundradena skiftat. Det finns de som hävdar att i det moderna västerländska samhället har vi slutat tala om döden i vardagslivet, god eller dålig. Vi lever isolerade i nuet och den gemensamma fond av erfarenheter av döden som fanns för några hundra år sedan har tonats ner. En sådan retorik gäller naturligtvis främst de västerländska samhällen som likt Sverige inte drabbats av krig under lång tid. I andra, t.ex. Israel, ingår döden sedan decennier i människors vardag.

Vokabulären kring döden kring död har förändrats i det moderna samhället. Att dö har bytts ut mot t.ex. gå hådan, somma in och avlida. Att vara döende skrivs om till
att vara i livets slutskede. Ett begrepp som diskuteras i sammanhanget är just
döendet. I litteraturen talas om värdig död eller världigt döende. I denna av-
handling används begreppet död för den ultimata ändpunkten i döendet. Med
en sådan definition blir det inte möjligt att formulera teorier om hur en god
eller dålig död upplevs av den som dör, eftersom sådana inte kan falsifieras.
Här döden är kan efterlevande endast äse. I sonens fall upplevde modern att
vägen mot döden var fasansfull också för sonen, men att han när han insett att
han var döende låt sig dö i förvissningen om att hans familjemedlemmar skulle
hjälpa varandra att leva vidare.

Om man uppfattar död som det absoluta slutet på livet och sorg som de käns-
lor som de efterlämnade får efter dödsfallet kan man inte sörja förrän döden
har inträffat. I litteraturen kring död och döende finns uttrycket anticipatorisk
sorg, d.v.s. sörjande i förväg. Modern sörjde inte i förväg. Medan sonen levde
var hon helt inställd på att bidra till att sonen hade ett så gott liv som han nå-
gonsin kunde. Hon hade fortfarande hopp om att kunna bidra härvidlag.

Döendet har man i ett dödsskylande samhälle ofta lämnat över åt professionel-
la att handha. I ett sådant samhälle kan inte medlemmarna naturligt stödja och
hjälpa dem som är döende, tala om döden, eller stödja dem som sörjer sina
döda. Det stöd som bygger på en gemensam erfarenhetsbas, vilken är en grund
för empati, blir då svårt för döende och sörjande att få i vardagen. Dock finns
empati att erhålla, vilket denna studie visar.

I olika kontexter upplevde modern empati. Fyra olika sammanhang diskuteras.

• **Institutionell empati**, som bygger på de värden en välfärdsstat vilar på och
som bör visas av dess tjänstemän. Sådan empati kan manifesteras i institutioners
flexibilitet, tillgänglighet, kontinuitet och den information som
ställs till förfogande. De gemensamma ansträngningarna från två universi-
tetssjukhus att bereda sonen möjlighet att tillbringa så mycket tid som
möjligt tillsammans med sin familj är ett exempel på institutionell empati.
Ett annat är det sätt på vilket försäkringskassans tjänstemän arrangerade
för moderna att komma tillbaka i arbete och det sätt som modern togs
emot på av sin arbetsgivare. Ytterligare ett är den omedelbara tillgänglig-
het som modern hade till sin familjeläkare.

• **Empati baserad i medkänsla**. Den medkänsla som modern upplevde kan
beskrivas bl.a. av orden erkännande, tillit, individualisering, flexibilitet
och bekräftelse. En sådan empati bidrog till att sjuksköterskorna i det
palliativa hemsjukvårdssteamet uppmanade och lärde familjemedlemmarna hur de bäst kunde göra sig nyttiga i vården av maken, pappan och sonen. Den som visar medkänsla känner själv, det ligger i begreppet. Modern upplevde empati i form av medkänsla från olika håll, det palliativa teamet, vänner, vissa arbetskamrater, familjeläkaren och föräldrar, vars barn också dött. Denna empati behöver inte grundas i en gemensam förlust, vilket nästa nivå av empati gör.


**Förlusten — en del av livet**

Sorgprocessen har ofta beskrivits som en stegvis progression mot ett liv som alltmindre präglas av förlusten. Vissa gemensamma drag i en sådan process har identifierats, men alltmer har man kommit att betrakta sorgprocessen som en individuell process. Eftersom varje sorg är unik är också varje sådan process unik. Det stöd i form av empati från olika håll som modern upplevde under
sonens palliativa vård och efter hans död bidrog till att hon efter tre år hade ett gott liv, d.v.s. med tanke på omständigheterna. Det finns i hennes process några vändpunkter, som var särskilt betydelsefulla och positiva. Några exempel ges nedan.

Den känslen av att bli förstådd av sjuksköterskorna och läkaren i det palliativa teamet och med dem tala om sonens förestående död var en vändpunkt för modern under den palliativa vården av sonen. Teamets samtal med familjemedlemmarna bidrog till att modern och sonen till slut kunde dela bedrövelse på ett sätt som de inte kunde innan teamet involverades i hans vård. För modern var detta väsentligt.

En röntgenundersökning av moderns friska hjärta gjorde att modern fick ett mantra att ta till när hon inte kunde sona. ”Du har ett friskt hjärta” upprepade hon för sig själv, när hjärtat tycktes hoppa runt i bröstet på henne. Samtal per telefon med vänner lugnade också.

Den handfasta hjälpen att lära sig se vad som går att kontrollera och vad som ligger utanför den egna kontrollen som modern fick av kuratorn, knuten till det palliativa teamet, hjälpte modern att få struktur på sin tillvaro efter sonens död.

Att få skratta åt sina tvångsföreställningar och inse att hon själv måste bestämma hur hennes liv skulle se ut i framtiden var en befrielse för modern, som psykoterapin åstadkom. Inte för att modern inte visste att leva sitt eget liv sedan tidigare, utan för att hon just efter sonens död inte kunde se hur hon överhuvudtaget skulle kunna leva ett drägligt liv. Sådana skratt kunde modern dela också med de föräldrar som ingick i den grupp av föräldrar som förlorat barn och som modern deltog i under någon tid efter sonens död.

Ett samtal med en tjänsteman på försäkringskassan gjorde det möjligt för moderna att komma tillbaka i arbetet i sin egen takt, med uppgifter som var möjliga för henne att genomföra. Detta och stödjande kolleger var en förutsättning för att hon efter ett år kunde arbeta som tidigare.

Fler exempel ges i avhandlingstexten.

En mycket betydelsefull vändpunkt inträffade när modern insåg att hon ofta ”grät sin sons tårar”. När hon såg sin sondotter lära sig simma, gå i luciatåget, dansa och leka grät hon ofta. Sådana situationer borde ju inga glädje. Så småningom kom hon underfund med att det var tanken på att hennes son inte fick
glädjas med och över sin flicka, som hon begrät. Hon sörjde allt han inte skulle komma att uppleva. “Han är död”, fick hon upprepa för sig själv. Inssikten om att hennes modersinstinkter fanns kvar även sedan sonen var död förvånade henne och var en vändpunkt i hennes sorg. I stället för att sörja att hennes son inte fick ta del av sin dotters liv försökte hon lära sig att vara tillfreds med att hon själv kunde vara delaktig i det.


**Diskussion**


Å ena sidan finns de som hävdar att ingen forskare kan fånga enskilda människors upplevelser. Det forskare samlar in genom intervjuer och enkäter är konstruktioner som berättarna eller de som besvarar enkäter väljer att presentera för forskaren.

Å andra sidan finns de som anser att de forskare som analyserar sina egna upplevelser är alltför känslovägen engagerad för att kunna göra en neutral tolkning av dessa.

I denna studie har tagits ställning för att det faktiskt går att tolka, lokaliser och contextualisera egna upplevelser. Moderns roll har varit tvåfaldig. Dels har hon som moder berättat i form av skriverier, dels har hon som forskare analyserat dessa. Att hon som forskare har med sig sina upplevelser in i analysprocessen kan ses som en nackdel, men också som en fördel. Nackdelen är att hon som forskare skulle kunna vara alltför engagerad i det som ska analyseras, fördelen att hon som forskare bär på en unik och kanske nödvändig erfarenhet för att ge analysen ett djup. En annan fördel är att hennes förförståelse är explicit, i varje fall i relation till upplevelserna.
Varje forskare bär med sig sin förförståelse in i forskningsprocessen. Det förefaller också troligt att forskare har känslor som härs med in i denna process. I stället för att se de dubbla rollerna som felkällor kan man se den möjlighet som de innebär. Tolkningarna, lokaliseringarna i teoretiska ramverk och kontextualiseringarna får bedömas av dem som tar del av dem. Om berättelserna och analysen av dem bidrar till ny kunskap om upplevelser av kommunikation i palliativ vård och i sorg då kan den studie som presenterats rymmas inom ramen för forskning. Ett sätt att undersöka huruvida ny kunskap genererats är att fråga dem som finns inom det undersökta området. Sådana frågor har ställts till sjuksköterskorna inom det palliativa teamet, familjeläkaren och läkare inom palliativ vård, som menar att kunskapsbidrag finns i studien. Vidare har tre artiklar publicerats i tidskrifter som bedömts inomvetenskapligt. Att familjemedlemmar känner igen sig i berättelserna, att forskare inom andra fält än palliativ vård lär sig av studien är naturligtvis intressant men inte argument för att studien ska betraktas som forskning inom det palliativa området.

De kunskapstillskott som studien bjuder kan sammanfattas i följande punkter:

- Begreppet död är tydligt separerat från döende. Det hopp som kan finnas under ett döende att bidra till en döendes livskvalitet lyfts fram.
- Studien är longitudinell och spänner över fyra år, något som inte är vanligt inom palliativ vård.
- Studien behandlar palliativ vård av en vuxen son. Inom detta område finns mycket få studier.
- Behovet av individualiserat stöd till sörjande har konkretiserats.
- Relationen över generationsgränserna i samband med gemensam förlust har analyserats. Detta område saknas i den tidigare forskningen.
- Frågan om vems tårar som gråts diskuteras i relation till anknytningsteori ur omsorgsgivarens perspektiv.
- Fokus ligger på positiva upplevelser av kommunikation, och studien kan därigenom bidra till en ökad förståelse av hur stöd till dem som vårdar förödde och som sörjer dem kan ges på ett individuellt och flexibelt sätt.
ACKNOWLEDGEMENTS

If my son had not been cared for by a palliative home care team this thesis would not have been written. In a devastating time I learnt to know nurses and doctors in a palliative home care team whose professional and personal qualities had a substantial value to me and my family. I hope that all who are in the same situation as we were will benefit from a care that is as medically excellent and emotionally compassionate as my son and the rest of our family received. Thank you all in the palliative home care team.

Björn Söderfeldt encouraged me to write the first article on palliative home care. He believed in the idea to make my own experiences data in the study. Thank you Björn.

The Department of Health and Society at Malmö University accepted me as a doctorate student. This implied that I was admitted to join courses in the area of health and care. My supervisor, Margareta Östman, believed in my study and opened up for me to be able to ventilate my articles scientifically together with her, other doctorate students and in seminars. Thank you Margareta for believing in me and in my writings.

Lars Sandman from a philosophical and Jonas Frykman from an ethnological perspective generously shared ideas at seminars that improved the analysis. Thank you for the input.

Together with my colleagues at the Department of Teacher Education at Malmö University I have learnt and still learn. Moreover—together with you I laughed and still laugh. Thank you for all your contributions. Specifically, I thank James Dresch, who kind-heartedly helped me find the English words I looked for.
My friends, in Sweden and abroad, thank you for supporting me, on a personal as well as a professional level. All of you who read my scripts, talked to me about ways of improving them and encouraged me to go on writing, not only supported me emotionally but also contributed to the thesis.

As a professor at the Department of Teacher Education at Malmö University I have benefited from the professor-program for some years, implying that I had time to think and write. Not until the professor-program was launched at Malmö University did I have time to concentrate on scientific work during working hours. Research was for many years carried out during evenings and nights. I thank those who decided on the professor-program and those who kept and hopefully will keep it, so that other researchers will benefit from it in the future.

My family, the extended included, is of utmost importance in my life at large and also in relation to the thesis. Family members have read my articles before they were submitted to the journals and encouraged me to send them in. Their contributions were of great value. Thank you for being there when I wrote and always.

And—at last—to my grandchildren specifically, who can not read the thesis yet, due to their age: Thank you for making me smile. Thank you for letting me into your lives. I hope that you can use the contents in this book later on as a means of learning what a difference you can make to other persons.

Segelstorp 2007

Lena
REFERENCES


Compassionate friend. Available 070325 at: www.compassionatefriend.com

Council of Europe (2003). Recommendation 24 by the member states committee of ministers to the member states on organisation of palliative care. Available 070318 at: http://www.nationellaadetforpalliativvard.se


Rubinstein Reich, L. (2001). *Mentorsprojektet Näktergalen: Möten mellan skolbarn och högskolestudenter* [The mentor project Nightingale: Meetings between school children and university students]. Malmö University: Department of Teacher Education. [In Swedish].


Wallskär, H. (2004). *Att vara närstående i livets slut* [To be close in the end of life]. Stockholm: Cancerfonden. [In Swedish].


Malmö University Health and Society Doctoral Dissertations
Ross, M. W. Typing, doing and being. A study of men who have sex with men and sexuality on the Internet. 2006:1

Stoltz, P. Searching for meaning of support in nursing. A study on support in family care of frail aged persons with examples from palliative care at home. 2006:2.

Gudmunsson, P. Detection of myocardial ischemia using real-time myocardial contrast echocardiography. 2006:3.


The publications are available on line. See www.mah.se/muep
This thesis is a mother’s story about support in palliative home care, grief and bereavement.

The communication between her adult dying son and herself, between a palliative home care team and family caregivers and in the support during the first three years of grief and bereavement is described and analyzed. Trust, flexibility, continuity, accessibility and empowerment were key concepts in the communication between the family caregivers and the palliative home care team. Empathy based on institutions, on compassion, on shared experiences and loss—but also empathy to self—contributed to the mother’s reconciliation.