# Facing bereavement

## Severe pre-loss grief symptoms and factors of complications during caregiving and bereavement in a nationwide caregiver cohort

PhD dissertation

Mette Kjærgaard Nielsen

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Aarhus

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Research Aarhus

## PhD-student:

Mette Kjærgaard Nielsen, MD, The Research Unit for General Practice, Department of Public Health, Aarhus University, Denmark

## Supervisors:

Flemming Bro, MD, Professor, PhD, Department of Public Health, The Research Unit for General Practice, Department of Public Health, Aarhus University, Denmark (main supervisor)

Mai-Britt Guldin, Cand. Psych., PhD, Department of Public Health, The Research Unit for General Practice, Department of Public Health, Aarhus University, Denmark & The Palliative Team, Department of Oncology, Aarhus University Hospital, Denmark

Anders Bonde Jensen, MD, Professor, PhD, Department of Oncology, Aarhus University Hospital, Denmark

Mette Asbjørn Neergaard, MD, PhD, The Palliative Team, Department of Oncology, Aarhus University Hospital, Denmark

## Assessment committee:

Jette Kolding Kristensen, MD, Associate Professor, PhD, Department of Public Health, Institute of General Medical Practice, Aarhus University, Denmark (chairman)

Carl-Johan Fürst, MD, Professor, PhD, Faculty of Medicine, Lund University, Sweden

Pernille Envold Bidstrup, Cand. Psych., Research Manager, PhD, Kræftens Bekæmpelse (The Danish Cancer Society), Denmark

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Mette Kjærgaard Nielsen, Skæring, January 2016

# CONTENTS

# PREFACE

*It feels like having an unwelcome guest in your house. It exhausts you. When you give up hoping that the illness will vanish, you must realise that it will take your loved one away. That is the condition for making it disappear. Then you are caught between 'keeping' or 'losing' your loved one together with the illness'.*

Female spouse to a terminally ill patient

# MOTIVATION

Being a caregiver to a terminally ill patient is highly demanding, and the consequences of a loss may extend far beyond the death of the patient. In my clinical work as a young doctor at the Department of Oncology and in General Practice, I was puzzled by the lack of focus on this fact in the health care system. Health professionals and especially the caregivers themselves seemed to underestimate the influence of this stressful situation. Severe illness, life crisis and grief are unavoidable factors in the life of a human being; they may provide an opportunity for personal development and these conditions of life can and should not be avoided. Still, the demanding situation of being a caregiver to a terminally ill patient exceeds the resources for a number of caregivers, and in this situation support from the health care system is crucial. In my clinical work, I experienced that this task was difficult to perform adequately. Hence, I found a high need for research on factors related to caregivers of terminally ill patients and their psychological distress during caregiving and bereavement. Specifically, knowledge on factors affecting psychological distress seems to be crucial for health professionals to provide support to caregivers. I hope the findings of this work will improve the basis for health professionals to increase their focus on caregivers and positively impact late palliative care trajectories for patients and caregivers whenever possible.

## OUTLINE

**Chapter 1** will introduce the research field of caregivers to terminally ill patients in a palliative care setting and during bereavement. This chapter will lead to a presentation of the four aims of the dissertation. The methods used to investigate these aims are described in **Chapter 2**, and a description is provided of the cohort on which Papers II-IV are based. In **Chapter 3**, the main results are presented. In **Chapter 4** the used methods are discussed including the generalizability of the findings. In **Chapter 5** the main results of the four studies investigating the aims are discussed. The conclusion of the dissertation in the light of the aims is presented in **Chapter 6**, while clinical implications of the results and topics for future research are suggested in **Chapter 7**. English and Danish summaries are presented in **Chapters 8 and 9. References** are placed at the end of each chapter. The four papers of the dissertation, **Papers I-IV**, are then presented followed by **Appendices A** and **B**, which contain the invitation letters and questionnaire mailed to patients and their caregivers at baseline, and **Appendices C** and **D**, which contain the invitation letter and questionnaire mailed to bereaved caregivers at follow-up, all in Danish.

This dissertation is based on the following four scientific papers:

Paper I: Nielsen MK, Neergaard MA, Jensen AB, Bro F, Guldin M. Do we need to change our understanding of anticipatory grief in caregivers? A systematic review of caregiver studies during end-of-life and bereavement. Published in *Clinical Psychology Review* 44 (2016) 75–93.

Paper II: Nielsen MK, Neergaard MA, Jensen AB, Bro F, Guldin M. Psychological distress, health and socio-economic factors in caregivers of terminally ill patients: a nationwide population-based cohort study. Published in *Supportive Care in Cancer,* 2016 Feb 18.

Paper III: Nielsen MK, Neergaard MA, Jensen AB, Vedsted P, Bro F, Guldin M. Predictors of complicated grief and post-loss depression in bereaved caregivers: a nationwide prospective cohort study. Submitted to *Palliative Medicine*.

Paper IV: Nielsen MK, Neergaard MA, Jensen AB, Vedsted P, Bro F, Guldin M.. Exploring caregiver’s pre-loss grief symptoms in palliative cancer care: a nationwide population-based study. In preparation for *Psycho-Oncology*.

# ABBREVIATIONS

| | |
|---|---|
| AG | Anticipatory grief |
| BDI-II | Beck's Depression Inventory-II |
| BSFC | Burden Scale for Family Caregivers |
| CCID | Couple's Communication about Illness and Death scale |
| CG | Complicated grief |
| DPM | Dual Process Model |
| ICG-R | Inventory of Complicated Grief-Revised |
| IRFF | Integrative Risk Factor Framework for the prediction of bereavement outcome |
| MG | Mai-Britt Guldin |
| MKN | Mette Kjærgaard Nielsen |
| PCS | Preparedness for Caregiving Scale |
| PG-13 | Prolonged Grief-13 scale |
| PGS | Pre-loss grief symptoms |

# CHAPTER 1:

## INTRODUCTION

Facing bereavement and the loss of a close relative may place caregivers in a vulnerable position. The demands caregiving may exceed caregivers' resources and result in high levels of burden and psychological distress with impairment of daily life functioning and major consequences for the journey into bereavement. Knowledge on factors indicating complications for caregivers during caregiving and bereavement is crucial to adequately support caregivers. However, only few population-based studies have investigated these factors. Especially the role of grief during caregiving seems to be sparsely investigated. These topics are the focus of the present dissertation, which will be introduced in this Chapter.

## BEING A CAREGIVER TO A TERMINALLY ILL PATIENT

Severe illness in a close relative is a big challenge for caregivers as it brings emotional suffering, grief and a large amount of practical demands. The need for informal caregiving seems to be increasing duo to the ageing populations in the western societies. Fortunately, most caregivers to terminally ill patients wish to take part in giving care to their close relatives (1,2). In a Danish qualitative study, caregivers expressed gratefulness for having the opportunity to participate in the care (3). Still, caregiving for a severely ill relative may restrict the caregiver's activities away from home, inflict fear due to the impending death and cause insecurity because of the patient's declining mental and physical health (4). A systematic review of the effects of providing care identified more than 200 problems and burdens related to caregiving responsibilities; this finding underlines the complexity of the situation as a caregiver (5). Frustrations regarding lack of information, uncertainty and dealing with the unpredictability of the future were reported. Furthermore, a combination of physical, social or emotional problems (including sleep disturbances, depression, fear and distress) was experienced. Grief was not mentioned directly, but the core grief symptoms of "dealing with feelings of separation and loss" were reported (5). Nevertheless, positive emotional experiences from caregiving were also reported (5).

Hence, caregivers must find the right balance between the burdens of caregiving and their resources. They might experience severe psychological distress if the demands exceed their resources (4,5). During bereavement, the grief symptoms initiated during caregiving play a central role. The patient's death may relieve caregivers from the burden and the demands of caregiving, but for a substantial number of bereaved caregivers, the loss results in severe psychological distress in terms of complicated grief or depression (6,7).

## CAREGIVING AS A PREVALENT ISSUE

Being a caregiver to a terminally ill patient is a challenge that all human beings are likely to face at some time point in their life. An American study found that approximately 70% of all deaths involve chronic and potentially life-threatening conditions, such as cancer, dementia or organ failure (8). In 2012, 52,325 persons died in Denmark (9) out of the Danish population of 5.6 million people (10). The most prevalent cause of death was cancer with 15,515 deaths, followed by 7,590 deaths due to heart disease and 3,454 deaths due to bronchitis and asthma (9). A number of these deaths are likely to have been sudden. Yet, in western countries, sudden death is less common than before (11) and many deaths must have been preceded by a terminal illness trajectory. Hence, caregiving for a terminally ill patient affects a large number of caregivers, who are facing bereavement.

In Denmark, patients and caregivers are provided with publicly funded health care services during a terminal illness trajectory. Hospital admissions are free of charge (12) and total drug reimbursement may be granted when a physician has assessed that the patient's illness is terminal (13). Furthermore, caregivers to terminally ill patients may take compassionate leave and have a statutory right to receive a special allowance during such leave (14).

## CENTRAL TERMS FOR CAREGIVERS IN A PALLIATIVE CARE SETTING

In this section, an outline will be provided of general definitions related to caregivers of terminally ill patients before and after the patient's death. Palliative care, caregiver, the terminal illness trajectory, bereavement, grief and non-bereavement grief are defined. Furthermore, pre-loss grief and grief symptoms are also presented as these two notions constitute the core factors of this dissertation. The remaining concepts and risk factors under study will be defined in the last sections of this Chapter.

The World Health Organization (WHO) defines palliative care as follows:

> *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, psychosocial and spiritual.* (WHO (15)).

Families are central in palliative care, and specifically individual family members may be caregivers to the patient. As other close relatives (such as friends) may be the closest relative for some patients, caregivers will, in this dissertation, include all informal caregivers, and the studies will focus on individual caregivers.

A *caregiver* has been defined as a *"'family-like' individual, nominated by the patient, and the 1 individual providing consistent help"* (6,16). Thus, the caregiver takes part in the *caregiving* of the patient, which involves provision of emotional support and/or practical/behavioral assistance for the patient (6).

A variety of terms have been used to describe the period of months preceding the patient's death. No consensus exists for the definition of the *terminal illness trajectory* and terms such as *terminal illness*, *end of life,* and *terminal care period* have been applied in prior research (17). A comprehensive review found that "actively dying" was used to describe a life expectancy of days to weeks for the patient, while the other terms were used in case of progressive illness with a life expectancy of months (17). Thus, in this dissertation all of these terms are used (sometimes in other combinations) to describe the period before the patient's death.

*Bereavement* refers to the loss of a significant relative and the period following the death of such relative (18).

*Grief* has been defined as the emotional reaction to bereavement (18), which will be specified as *bereavement grief* when needed. However, *grief* can also be seen as the emotional reaction to another important non-bereavement loss, for instance due to natural disasters, chronic illness or disability, which is called *non-bereavement grief* (19). Grief symptoms of such reaction in caregivers to terminally ill patients before the patient's death will be termed *pre-loss grief symptoms* (PGS).

Grief symptoms encompass psychological, cognitive, social, behavioral and physical manifestations (18,20) and can develop to a disabling level. Core *grief symptoms* are yearning for and preoccupation with the lost person (21,22). Other symptoms of grief are troubles with accepting the loss, avoidance of reminders of the loss, feeling that life is meaningless, bitterness, emotional numbness, feeling stunned, feeling confused about one's role in life and having difficulty trusting other (22).

## BEREAVEMENT

For some caregivers the death of their close relative might relieve the psychological distress of caregiving. Bereavement of a close person causes grief as a natural reaction. Within months or years from the death the majority of caregivers will adapt to the loss

(23). Still, a substantial minority develops disabling conditions such as complicated grief (CG) and depression.

### Complicated Grief

CG is a symptom complex with intense, persistent grief in the bereaved caregiver lasting beyond six months after the loss, which impairs the psychological, social and daily functioning (21,24,25). Core symptoms are yearning and longing for the deceased, difficulties accepting the loss, preoccupation with the deceased and reactive distress symptoms (21,24,25). Although severe grief has been described for several decades in the literature (26), an empirically derived complex of grief symptoms was not established until the 1990s (27).

In this dissertation, the term CG is used about this condition involving severe persistent complications during bereavement. However, no consensus has been reached on the name, and the term *prolonged grief* is also widely used for the same condition (21,28,29). A growing amount of studies point to CG as a debilitating condition encountered by a number of bereaved caregivers, and these findings may indicate a need for support (25,26). CG was proposed for inclusion in the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5). Accepting CG as a diagnosis may improve identification and treatment options for the benefit of caregivers (30). However, CG was not included but was placed in an appendix of conditions for further study as an entity called "persistent complex bereavement disorder" (24). The condition has now been proposed for the *International Classification of Diseases*, 11th version (ICD-11) (28), which is due by 2018 (31). Symptoms and proposed diagnostic criteria are displayed in Table 1.1 on the following page.

CG has been investigated using different measurement tools. While the *Inventory of Complicated Grief-Revised* (ICG-R) (34,35) measures grief symptoms, the *Prolonged Grief-13* scale (PG-13) includes a criterion of duration of symptoms for at least six months and a criterion regarding impaired functioning (8,12). Moreover, to fulfill the criteria for CG on the PG-13, the caregiver must both report high scores on grief symptoms and must have been functionally impaired for at least six months. Hence, the PG-13 results in lower prevalence rates do to more restrictive scoring. The prevalence of CG measured by PG-13 was found to be 7% in a population-based study (36), and the prevalence was found to be in the range of 6-40% in different study populations and measured by different scales (34,37-39).

*Table 1.1. Suggested diagnosis criteria for CG (22,25,28) and the diagnosis criteria for depression according to the ICD-10 (32,33).*

| | *Complicated grief* | *Depressive episodes* |
|---|---|---|
| **General Criteria** | - Disturbance following the death of a close person<br>- Key symptoms for at least 6 months or longer depending of cultural and contextual factors | - Disturbance of lowered mood unresponsive to circumstances<br>- Symptoms must last at least two weeks |
| **Core symptoms** | - Pervasive yearning or longing for the deceased<br>- Persistent preoccupation with the deceased | - Depressed mood<br>- Loss of interest and enjoyment<br>- Reduced energy and decrease in activity |
| **Associated symptoms** | - Difficulties accepting the loss<br>- Sadness, inability to have a positive mood<br>- Feeling one has lost a part of one's self<br>- Anger about the loss<br>- Guilt, blame<br>- Denial, emotional numbness<br>- Difficulty in engaging with social or other activities | - Reduced concentration, cognition and attention<br>- Reduced self-esteem and self-confidence<br>- Ideas of guilt and unworthiness<br>- Ideas or acts of self-harm or suicide<br>- Disturbed sleep, diminished appetite<br>- Agitation or psychomotor retardation<br>- Reduced self-esteem and self-confidence |
| **Severity** | Complicated grief:<br>- At least one core symptom and five associated symptoms*<br>- Sufficiently severe to cause significant impairment in the person's daily functioning | Moderate or severe depressive episode:<br>- Two-three core symptoms and at least four-five associated symptoms<br>- Is likely to cause great difficulty in continuing ordinary activities |

Hence, CG seems to be an empirically established symptom complex revealing debilitating suffering in a substantial proportion of bereaved caregivers. Specific psychotherapy for complicated grief has been found effective (24,25), and studies have been investigating risk factors of CG, which may aid early identification of caregivers with CG (24,25,40). Risk factors related to socio-economy, personal vulnerability and palliative care will be addressed later.

### Depressive episodes

Depressive symptoms are common both during caregiving and bereavement. In existing literature it has been discussed whether CG and depression are distinct conditions and several studies seem to have demonstrated diverging symptom complexes for CG and depression (41-43).

A depression is an affective disorder, which highly compromises the daily life and well-being of the depressed person. Core symptoms are low mood, reduced energy and lack of interest in activities (32,33,44,45). A clinical interview is required to diagnose a person with a depression (32), but this is not feasible in large-scale population-based studies. Thus, self-report questionnaires are widely used in research to obtain information on the study population's psychological distress, for instance the Beck Depression Inventory-II (BDI-II) (46) or the Distress Thermometer (47). A self-report questionnaire may provide data on the number of depressive symptoms and the severity of these symptoms. Validated scales, such as the BDI-II, may provide a manual for scoring responses as sum scores and categorical scores indicative of mild, moderate or severe depression with cut-points based on the diagnostic interview (46).

According to a review on caregivers to hospice patients, 27-55% had depressive symptoms (48). The level of depressive symptoms was found to be higher in caregivers than in patients, and more caregivers reported high levels of depressive symptoms close to death (49). During bereavement, 15% of bereaved caregivers in a Danish specialized palliative care setting had depressive symptoms (34). In comparison, the prevalence of depression in the general population is approximately 3% (45,50). Furthermore, bereavement may have widespread impact. For instance, the loss of a parent early in life has been found to increase the risk of hospitalization due to depression (51).

Caregiver's depressive symptoms before and after bereavement have been investigated as person-centered "grief trajectories" (52,53). In total, 1/4 of caregivers had a high level of depressive symptoms after their loss. Of these, 15% had a high level of depressive symptoms both before and after the patient's death, and 9% developed depression post-loss (52). In addition, 10% had a high level of depressive symptoms before the death, which improved after the death (52). Improvements in the caregiver's psychological well-being after the death of the patient do not seem to have been considered in bereavement literature until recently (23). Depression is well-established as a diagnosis worldwide, and both caregiving and bereavement has consistently been associated with increased risk of developing a depression in caregivers. Because depression is a debilitating condition affecting daily functioning and social life, it should be diagnosed in caregivers during caregiving or bereavement, and treatment should be initiated (44,45).

## RISK FACTORS OF ADVERSE BEREAVEMENT OUTCOME IN CAREGIVERS

Caregiver's development of adverse bereavement outcome such as complicated grief and depression, may depend on a range of factors that interact in a complex manner (20,54). To navigate in the investigation of these risk factors, we searched for an empirically based model and found the *"Integrative risk factor framework for the prediction of bereavement outcome*" (IRFF) by Stroebe et al (54) to be best suited for the purpose of this dissertation. The authors introduced the IRFF to provide an overview of the multiple factors contributing to the development of adverse bereavement outcome and to facilitate systematic analysis of these factors (54).

The comprehensive IRFF (Figure 1.1 on the following page) comprises four categories of predictive factors for bereavement outcome:

(A) the *nature of the stressor* (e.g. type of death; sudden, unprepared, untimely, type of loss: spouse, child),

(B) *intrapersonal* factors in caregiver (e.g. previous depression, socio-economic factors),

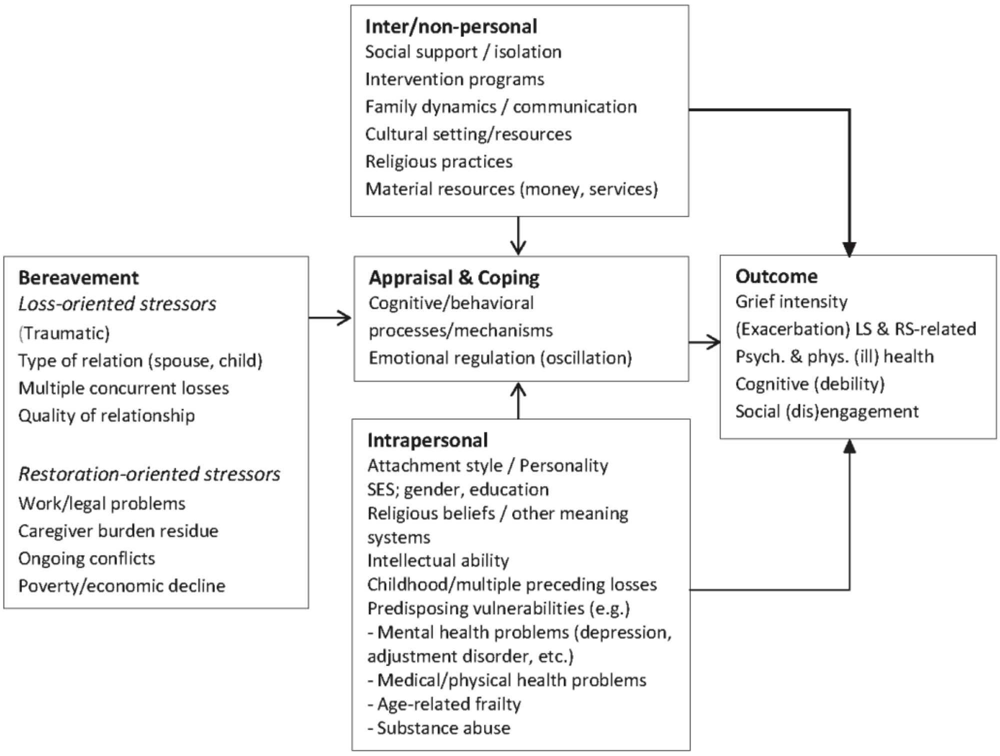
(C) *interpersonal* factors in caregiver (e.g. family dynamics, social support) and

(D) *appraisal and coping* strategies (cognitive processes and emotion regulation).

While the first three categories comprise predefining factors for the bereavement outcome, the latter category entails mediators in the process and is placed between the stressors and the outcome (54).

The IRFF builds on theoretical bereavement models (54): The Dual Process Model of coping with bereavement (DPM) by Stroebe et al. (55), the cognitive stress, appraisal and coping theory by Lazarus and Folkman (56) and attachment theory by Bowlby (57). The DPM is empirically supported and constitutes a core theory of the IRFF. Loss- and restoration-oriented stressors are part of the bereavement (Category A). Loss-oriented stressors include grief, relocation of bonds to the deceased and avoidance of restoration, while the restoration-oriented stressors involve attending to the life changes, doing new things and avoidance of grief (55). Coping with bereavement is a dynamic regulatory process in which *oscillation* between these loss- and restoration-oriented stressors may facilitate psychological adjustment to the new situation (55).

*Figure 1.1. The integrative risk factor framework for prediction of bereavement outcome.*



Using the IRFF as a framework (54), we aimed to investigate predefined factors related to socio-economic conditions and predisposition for depression (intrapersonal factors), communication about dying between the caregiver and the patient (interpersonal factors) and the type of loss (the nature of the stressor). Furthermore, situational factors related to caregiver's reactions during the patient's terminal illness trajectory (palliative care-specific factors) were encompassed in the latter category for the purpose of this study. The psychological process of appraisal, coping and emotion regulation was not assessed in the questionnaire study of this thesis. Still, the processual factors and grief theories entailed in the IRFF play an important role in the interpretation of the findings related to the aims of this dissertation.

In summary, in this dissertation the IRFF factors included are: depressive symptoms, personal relation, socio-economic factors, grief symptoms during caregiving, caregiver burden, preparedness for the impending death and communication about dying. Factors that have not been introduced before will briefly be described in the next section.

### Personal relation and socio-economic factors

The relation between the patient and the caregiver is likely to play a role for the bereavement outcome. In studies regarding the relation to adult patients, losing a spouse has been associated with worse bereavement outcome than losing a parent (20,36,40).

Socio-demographic factors have also been associated with adverse bereavement outcome. Female gender in the caregiver has been found to be a risk factor in some studies (36,40), although a review study found no gender difference (58), and others found male gender to be a risk factor (20). Furthermore, the mortality for men has been shown to be increased during bereavement (20). In a population-based study, old age was found to be associated with higher risk of complicated grief (36). However, in a review, young age was found to be associated with adverse bereavement outcome (20). Furthermore, low educational level has been associated with adverse bereavement outcome (20,40). As persons with low education might be more vulnerable to psychological distress (54), it is uncertain whether the found effect is an effect of bereavement or a general effect (54).

### Grief symptoms during caregiving

Grief symptoms before the patient's death may be termed *pre-loss grief*. In the literature, it has also been termed *anticipatory grief*. Clinical observations by the American psychiatrist Erich Lindemann (59) were interpreted in the light of the hypothesis of grief work by Freud, and this led to the assumption that caregiver's grief symptoms before the death could be seen as grief work initiated before the loss of a loved one. Grief work entails discontinuation of attachment bonds to the relative and was formerly thought to be necessary for adjustment to the loss. Thus, anticipatory grief was interpreted as a process of discontinuation of "bonds to the deceased" and was, therefore, assumed to alleviate the bereavement outcome.

Contrary to this, contemporary grief theory suggests that it is helpful to continue the bonds to the deceased (60), and the concept of anticipatory grief has been gravely questioned (61-64). Caregiver's grief symptoms before the patient's death have been linked with the losses of a future together with the patient and with losses and uncertainties in daily life due to the illness along with witnessing the patient's loss of e.g. bodily functions and personal abilities (61). Grief symptoms before the death of the patient refer to the reaction to a non-bereavement loss (19). Emerging research on grief symptoms measured in other non-bereavement loss situations e.g. loss of a job and divorce points to similar levels of grief symptoms in connection with such losses and during bereavement (19). Non-bereavement grief symptoms were explained by the loss of an identity-defining job or relationship, which was shown to initiate more grief symptoms than a loss unrelated to personal identity (19).

Recent studies have investigated grief before the loss (39,63,65). They studied grief symptoms measured on a pre-loss version of a complicated grief measurement tool and found that 15% of caregivers reported severe levels of pre-loss grief. The condition was associated with later development of complicated grief (39,65) and depression (63). Severe pre-loss grief symptoms were associated with female gender (66), spousal relation (39,65,66), low education, young patient age (67), living with the patient (39,66,67), prior stressful life events, pessimism (68) and depression before the loss (67,68). Still, studies on pre-loss grief are few and knowledge on associated factors and bereavement outcome is sparse.

### Caregiver burden

Caregiver burden is related to the caregiver's perception of an adverse effect of caregiving on their emotional, social, financial, physical and spiritual functioning (69). Scales measuring caregiver burden have been developed for research purpose and clinical care. Such scales include items addressing emotional issues (such as feeling exhausted due to caregiving), social issues (such as being unable to leave the home) and practical issues (such as participating in the care) (70).

Caregiver burden has been associated with depression during both caregiving and bereavement (69,71). Risk factors for caregiver burden identified so far are female gender, low education, sleep deprivation and difficulty coping with the situation (69). A high level of caregiver burden has been reported in as many as 32% of caregivers in an American large-scale survey of caregivers (69).

### Preparedness for the impending death

Preparedness for death has been defined as the caregiver's perception of his or her readiness for the impending death of the patient (72). In a qualitative study, preparedness has been described to have cognitive, affective and behavioral dimensions (73). Furthermore, it has been found to be influenced by uncertainties in the illness trajectory (74,75).

Low preparedness has been associated with complicated grief in a few studies (74,76,77), but only one study has a prospective design (76). A single-item question (“How prepared were you for your relative’s death) measured preparedness in these studies (74,77-79). Hence, studies on preparedness are lacking, especially prospective studies, and there is a need for more prospective studies to establish if preparedness for death could be a risk factor for adverse bereavement outcome.

### Communication about dying

Diverging results have been found in the few studies investigating communication about illness and death in the family (80,81) as one study suggests that low communication in the family about dying increases the risk of adverse bereavement outcome (80), whereas another study assessing the communication retrospectively found that a high level of communication was a risk factor for bereavement distress (81). These two studies assessed communication with different assessment tools, which limits the comparability. Thus, studies investigating communication in the family about dying as a risk factor for bereavement outcome are needed as knowledge on the effects of communication is crucial for terminal care.

## KNOWLEDGE GAPS IN RISK FACTORS FOR CAREGIVER COMPLICATIONS

The situation of being a caregiver to a terminally ill patient may be influenced by a number of factors that all interact in a complex pattern. Situational factors related to the caregiving context seem to encompass the emotions, burdens and responsibilities encountered in palliative care. The role of the caregiver’s grief symptoms before the death of a close relative seems sparsely explored. Furthermore, studies focusing on the significance of caregiver’s grief symptoms during caregiving, caregiver burden, preparedness for death and communication about illness and death for bereavement outcome and the complex interplay of these factors are scarce. Furthermore, personal factors regarding socio-economic factors, relation to the patient and depressive symptoms are also likely to play a role. For instance, we hypothesized that being a partner to the patient may be associated with both high caregiver burden and severe pre-loss grief symptoms, and this association may be further affected by low educational level.

In general, population-based prospective studies may be useful to gain insight into the prevalence, characteristics and significance of factors, which may hold the potential for support, treatment or practical arrangements during caregiving. Thereby, the experience of the caregiving period may be optimized and bereavement outcome may be improved.

## INTRODUCTION AT A GLANCE

- Caregivers to terminally ill patients are in a vulnerable position as they meet multiple challenges, uncertainties and losses due to the patient's deterioration at the end of life.
- A considerable number of caregivers have high levels of psychological distress during caregiving and develop bereavement complications, such as complicated grief or depression.
- The extent of psychological distress during end-of-life caregiving and bereavement has not previously been established in a Danish population-based setting.
- Caregivers with high levels of psychological distress are likely to need support, and knowledge on predictors of adverse bereavement outcome is essential for health professionals to identify caregivers in need of targeted support.
- Psychological distress may be inflicted by several factors in a complex interplay. *Stroebe et al*. proposed the *Integrative Risk Factor Framework for Prediction of Bereavement outcome* (IRFF) (54). In the present dissertation, this framework is used to investigate predictors of psychological distress and intrapersonal, interpersonal and situational factors related to caregiving in an end-of-life trajectory.
- A high level of intense grief during caregiving that impairs daily life is termed *severe pre-loss grief symptoms* (PGS). Severe PGS may indicate a need for support, but the concept remains little studied. Hence, the role of PGS needs to be established.
- In this dissertation, severe PGS and risk factors of complications during caregiving and bereavement are investigated using the IRFF.

## AIMS OF THE DISSERTATION

The objective of this dissertation was to gain insight into the role of caregiver's grief during caregiving, extent of psychological distress and predictors of adverse bereavement outcome with a particular focus on palliative care-related factors. In order to do so, the aim was divided into four sub-aims:

1) To investigate the role of pre-loss grief symptoms and preparedness for death for adverse bereavement outcome in existing studies.
2) To estimate the prevalence of pre-loss grief symptoms, depressive symptoms, preparedness for death and caregiver burden in caregivers to terminally ill patients in a nation-wide population-based cohort.
3) To compare levels of grief and depressive symptoms before and after the patient's death and investigate socio-economic and palliative care-specific predictors of complicated grief and post-loss depression.
4) To investigate severe pre-loss grief symptoms and associations with socio-economic factors, depressive symptoms and palliative care-specific factors.

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# CHAPTER 2:

## METHODS AND MATERIALS

This dissertation builds on a systematic review (*Paper I*) and a nation-wide, population-based cohort study (*Papers II-IV*). The cohort study is based on a combination of questionnaire data and register-based data. A baseline questionnaire to caregivers to terminally ill patients provides data for *Papers II and IV*, while both baseline and follow-up questionnaire data was included in *Paper III*. Table 2.1 provides an overview of the studies of this dissertation and this Chapter presents the study methods in detail.

*Table 2.1. Overview of study characteristics of Papers I-IV.*

| Paper | Study design | Study population | Data sources | Primary variable(s) |
|---|---|---|---|---|
| I | Systematic review. | Adult caregivers to adult patients with an end-of-life illness. 34 included studies with an average of 204 participants in each study (N=6,936). | Search databases: PubMed, PsycInfo, Embase, Cinahl, Web of Science. | Anticipatory grief/pre-loss grief.<br>Preparedness for death.<br>Bereavement outcome*. |
| II | Cross-sectional prevalence study. | Caregivers to patients registered with drug reimbursement due to terminally illness. Patient population was sampled in 2012 and sent a questionnaire for caregivers. Total cohort of baseline participants. N=3,635. | Registers: CRS, CTR, SD, DCR, NPR.<br>Baseline questionnaire. | Socio-economic factors.<br>Pre-loss grief symptoms.<br>Depressive symptoms.<br>Caregiver burden.<br>Preparedness for death. |
| III | Longitudinal cohort study. | Caregivers to patients registered with drug reimbursement due to terminally illness in 2012. Participants at baseline pre-loss and at follow-up six months post-loss. N=2,125. | Registers: CRS, CTR, SD, DCR, NPR.<br>Baseline questionnaire.<br>Follow-up questionnaire. | Outcome at follow-up:<br>Complicated grief.<br>Post-loss depression.<br>Predictors at baseline:<br>Palliative care-specific factors.<br>Socio-economic factors. |
| IV | Cross-sectional study. | Caregivers to patients registered with drug reimbursement due to terminally illness in 2012. Caregivers to cancer patients who completed the pre-loss grief assessment at baseline. N=3,113. | Registers: CRS, CTR, SD, DCR, NPR.<br>Baseline questionnaire. | Palliative care-specific factors.<br>Socio-economic factors. |

CRS: Civil Registration System CTR: Central Reimbursement Register. SD: Statistics Denmark, DCR: Danish Cancer Registry. NPR: National Patient Register. *Bereavement outcome: e.g. complicated grief, depressive symptoms and anxiety. ** Palliative care-specific factors: Pre-loss grief symptoms, depressive symptoms, caregiver burden, preparedness for death, communication about death and dying.

## THE SYSTEMATIC REVIEW (PAPER I)

The method of the systematic review (*Paper I*) will be addressed in this section.

### *Study design*

We conducted a systematic review to investigate the existing body of literature regarding the effect of grief during caregiving and preparedness for the impending death on bereavement outcomes (*Paper I*). The key variables were anticipatory grief, pre-loss grief and preparedness for death, and any kind of bereavement outcome was included. The systematic review was conducted in accordance with the *Preferred Reporting Items for Systematic reviews and Meta-analyses* (PRISMA) statement (1), and the PRISMA 2009 Checklist was completed (*Supplementary material A, Paper I)*. The method was documented in a review protocol (2).

### *Search strategy and eligibility criteria*

Searches were conducted in five databases: PubMed, PsycInfo, CINAHL, Web of Science and Embase. The search was limited to English language and the time period from 1990-2015. The following search terms were used: *(anticipatory grief* OR *preparedness)* AND *(family caregiver* OR *bereavement* OR *grief)*. Details on the search strategy were provided in a PICO diagram and screen prints of the search strings (*Supplementary material B, Paper I)*.

The identified studies were assessed and excluded if they did not meet all of the following inclusion criteria:

1. Studies concerning caregivers of adult patients,
2. Studies on patients in an end-of-life trajectory,
3. Studies using a tool for measuring AG or preparedness.

Conference abstracts, expert opinions, clinical guidelines, and reviews were excluded.

### Study selection and data extraction

Initially, 1,192 hits were found. After removal of doublets, abstracts of 615 hits were investigated by MKN and randomly checked by one of the co-authors (MG). Papers were excluded if they did not meet the inclusion criteria. We added a single additional study after hand-search of reference lists. In total, 70 full-text papers were reviewed.

Studies causing doubt about inclusion were discussed by MKN and MG, and finally we included 34 studies (*Figure 1, Paper I*).

The data extraction process was pilot tested by MKN for 10 studies and refined accordingly by MKN and MG. From each study, data was retrieved on: source, study design, definition, measurement tool and study results. A quality assessment of study design was performed in line with a prior review study (3) (*Supplementary material C, Paper I*), and it was used to assess the risk of bias at study level, while definitions and measurements of AG/preparedness were evaluated for consistency before the data synthesis to assess the risk of bias on outcome level. A longitudinal study design was required to provide information on the causal effect of AG and preparedness on bereavement outcome (main aim), and these studies had better scores in the quality assessment than cross-sectional studies. Therefore, they were weighted higher in the data synthesis.

## THE DANISH CAREGIVER COHORT STUDY (PAPER II-IV)

We conducted a nation-wide prospective cohort study to investigate psychological distress during caregiving with a focus on pre-loss grief and to analyze effects of pre-loss factors on post-loss psychological distress. Data was collected from Danish population-based health registers, a questionnaire to caregiver to terminally ill patients (baseline) and a questionnaire to participating caregivers to patients, who died within six months (follow-up) and linked via the Danish *civil registration number* (CPR-number).

In *Paper II,* prevalence of factors related to caregiving including the core factor of pre-loss grief symptoms are presented in a cross-sectional study design, which is often called a *prevalence study* (4).

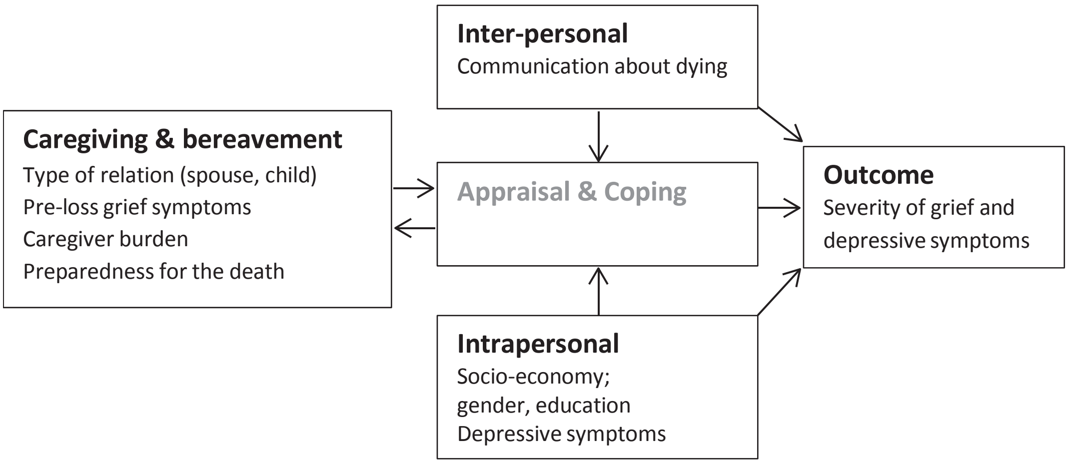
In *Paper III,* associations between possible predictors related to palliative caregiving and socio-economy and complicated grief and post-loss depressive symptoms are analyzed in a longitudinal study design using pre-loss baseline questionnaires and post-loss follow-up questionnaires.

*Paper IV* addresses associations between severe pre-loss grief symptoms and palliative caregiving-specific and socio-economic factors in a cross-sectional study design based on data from the baseline caregiver cohort restricted to caregivers to patients with cancer and participants who completed the pre-loss grief scale.

### Analytical framework

The aims of this study were to describe the prevalence of caregiver reactions during caregiving (*Paper II*), to investigate predictors for adverse bereavement outcome (*Paper III*) and to analyze factors associated with severe PGS at baseline (*Paper IV*). Hence, in all studies a range of factors were assessed. To provide an overview of factors related to bereavement outcome, we searched the literature and found the IRFF (see *Chapter 1,* Figure 1.1), which further integrates a theoretical foundation for these factors (5). The factors of interest to pursue the aims of this dissertation are highlighted in bold in the modified model of the IRFF (Figure. 2.1). Furthermore, we present a modified pre-loss version of the framework to provide an overview of factors associated with PGS.

***Figure 2.1**: Framework for personal and palliative care-specific factors inspired by "The integrative risk factor framework for the prediction of bereavement outcome" (5).*



### Identification of the caregiver population

The Danish health care system is based on taxes. Health care is free of charge for all citizens, and all expenses during a hospital admission are covered (6). Prescription-only medicine is partly covered through a general reimbursement. Furthermore, individual drug reimbursement can be provided in special cases after a physician assessment and a formal registration at the Danish Medicines Agency (7).

Terminally ill patients staying at home or at nursing homes are entitled to free medications equal to patients staying at hospital after registration with an individual drug reimbursement for terminally ill patients (7). Physicians may apply for formal registration for drug reimbursement for the terminally ill (in Danish: "terminaltilskud") at the Danish Medicines Agency for patients, who are assessed to have no curative treatment options and a limited life expectancy (7). Within 1-2 working days, patients are registered in the Central Reimbursement Register (CTR) and receive prescription medicine free of charge at all Danish pharmacies, which are linked to the CTR (7). Around 12.000 Danish citizens receive drug reimbursement due to terminally illness each year (8). No detailed report have yet been published on this patient group, but data from a report on terminally ill cancer patients sampled from the CTR in 2011 show that approximately 90% of patients granted drug reimbursement for the terminally ill were suffering from cancer (9).

We utilized the opportunity to receive information on Danish patients assessed terminally ill by a physician in order to get in contact with their closest caregivers. We mailed a study participation letter and a questionnaire to these patients for their caregivers. These caregivers comprise the Danish Caregiver Cohort 2012, which forms the basis for Papers II-IV in this dissertation.

## Register-based data sources

### *The CPR number and the Danish Civil Registration System (CRS)*

All Danish citizens are allocated a 10-digit personal identification number, the CPR-number (10,11). The CPR-number is used in governmental registration systems including the health care system to store and process information on the citizens and enables access to high validity information on an individual level (10-12).

The six first digits in the CPR-number consist of the person's birth date and the last digit is even for women and odd for men. Thereby, information on the patient's and the caregiver's age and gender can be obtained from their CPR-numbers (11). The Danish Civil Registration System (CRS) contains information on address change of address, migration and deaths of Danish citizens, which is up-dated on a daily basis (11,13). For the cohort study (*Paper II-IV*), we obtained information on postal addresses for patients at baseline and for caregivers at follow-up, and we checked the date of patient's death in the CRS. Furthermore, vital status was checked on patients at baseline and caregivers at follow-up both before mailing questionnaires and before mailing reminders.

### *Statistics Denmark*

Statistics Denmark is a Danish institution collecting, processing and publishing statistical information of Danish citizens and society (14). Researches have the possibility to gain access to anonymized data on a predefined cohort after approval from the Danish Health Authorities (15). In this study, questionnaire data from the caregiver cohort was transferred to Statistics Denmark. Then data was linked through CPR-numbers at an individual level for *Papers II-IV* on educational level (<10 years, 10-15 years, >15 years) (16), income (<20,000, 20,000-34,999, 35,000-50,000, >50,000 euros/year), residency (owned, rented), cohabitation status (married/cohabiting, living alone), children living at home (yes, no), ethnicity (immigrant/descendant, non-immigrant/descendant) and urbanicity (<4,999, 5,000-49,999, >50,000 inhabitants in the community) (10,15). CPR-numbers were anonymized before the linked data set could be accessed by authorized researchers via a secure IT-connection (15).

### *The Danish Cancer Registry (DCR)*

The DCR is a national research and surveillance register commenced in 1943 (17). Data on Danish cancer patients is collected and includes information on cancer diagnosis according to the 10th *International Classification of Diseases* (ICD-10), date of diagnosis, cancer type, site morphology and history of cancer, etc. If a patient develops more than one primary cancer, each cancer is registered in an individual record (17). For *Papers II-IV*, patient's latest recorded cancer diagnosis code within the last ten years was retrieved including all ICD-10 codes for malignant cancer diagnosis (C00-C97) excluding C44 (non-melanoma skin tumour). The completeness of the DCR is considered high (17). Therefore, patients without a cancer diagnosis in the DCR were categorized as non-cancer patients. For analysis, patient's terminal diagnosis were categorized as colorectal cancer (C 18-20), lung cancer (C 34), breast cancer (C50), prostate (C 61), haematological (C 81-96), other cancers (remaining C codes) or as non-cancer for patients not registered in the DCR.

### *The Danish National Patient Register (DNPR)*

In the Danish secondary health care system, data from Patient Administration Systems are required to be delivered to the DNPR, which has an almost complete follow-up (18).

The purpose of the DNPR is to form the basis for hospital statistics, disease monitoring and research (18). For this dissertation, the DNPR was used to obtain information on patients, who were not registered in the DCR. ICD-10 codes for these patients were obtained from the DNPR from registrations in connection with the patient's hospital contacts on life-threatening, chronic non-cancer conditions, which were likely to have caused the formal registration with drug reimbursement for terminal ill. The conditions were: Chronic Obstructive Pulmonary Disease (COPD), heart failure, kidney failure, Parkinson's disease and dementia (*Papers II-III)*. Furthermore, information on caregiver's hospital contacts was retrieved to calculate the Charlson comorbidity index (CCI) for *Paper II* (19).

### Questionnaire data

Two questionnaires were developed: one for caregivers at baseline and one for caregivers at follow-up six months post-loss (Appendices B and D (in Danish)). The included variables were chosen according to the aims of the studies. We used existing scales with psychometric testing whenever possible; otherwise, ad hoc questions were constructed. When we selected included tools, we took into account the use of scales and items in existing literature and on the research group's prior experiences with the tools from comparable caregiver studies in a palliative care setting. The order of questions and scale is important and may impact caregiver's assessment of psychological morbidity (20). Each questionnaire began with questions of neutral emotional content, moved on to scales measuring caregiver's reactions, psychological distress, caregiver's communication about illness and death and prognostic information. Both questionnaires included questions about assessment of support from health professionals and wishes for place of death at the final pages, and these questions were not analyzed for this dissertation.

#### *Measurements*

The outcome measures were PGS, depressive symptoms, caregiver burden, preparedness and health status at baseline and CG and depressive symptoms at follow-up.

*Complicated grief* (Papers II and IV) was measured by the PG-13 (21,22). The PG-13 scale was translated into Danish according to the WHO recommendations (23). Psychometric testing with factor analysis of this Danish version of the PG-13 is currently being performed at the Research Unit for General Practice and in the preliminary analyses the scale seems to be valid. Caregivers were divided into two groups based on whether they fulfilled the criteria for complicated grief (yes, no) (21,22).

To assess *pre-loss grief symptoms* in caregivers at baseline, we chose a pre-loss version of the Prolonged Grief-13 scale (PG-13) (21,22), because it was based on criteria corresponding to a severe complicated grief reaction (24,25). Therefore, the Danish version of the PG-13 was adapted to a pre-loss setting. The PG-13 contains an item (item 3) regarding the duration of the symptoms, which was not applicable pre-loss. Therefore, this item was omitted in line with prior studies (24,25). Thus, pre-loss grief was measured on a 12-item pre-loss version of PG-13 scale. The PG-13 item 10 (on "moving on") seemed not to be appropriate in a pre-loss setting. Therefore, we changed item 10 into an item concerning "hard to concentrate" based on a pre-loss version of the Inventory of Complicated Grief-scale (pre-loss ICG) reported by Tomarken et al (26). The pre-loss PG scale was scored according to the PG-13 criteria scoring without the duration criterion according to prior studies (24,25).

*Depressive symptoms* (Papers II-IV) were measured similarly at baseline and at follow-up by the 21-item Beck's Depression Inventory-II (BDI-II) (27). A sum score was calculated and caregivers were categorized (none, mild, moderate, severe) based on the sum score according to the manual (27) and further dichotomized (none-mild, moderate-severe). An additional category (does not apply) was added to item 21 on sexuality as the question was considered offensive in a previous caregiver study (28).

The *Burden Scale for Family Caregivers* (BSFC) measured caregiver burden as a sum score and was categorized according to the manual (29-31). *Preparedness for the impending death* was assessed by the single-item question *'How prepared are you that your relative might die from illness?'* which had been used in a retrospective version in prior studies (32-35). The response categories (1: "not at all", 2: "to a low degree", 3: "to some degree", 4: "to a great extent") were dichotomized (1-2: low, 3-4: high). Health The 36-item *Short Form Health Survey* (SF-36) measured *health status* on a physical component score (PCS) and a mental component score (MCS); these ranged from 0 (worst) to 100 (best) (36-38).

Furthermore, exposure measures from the baseline questionnaire included the 5-item *Couples' Communication about Illness and Death scale* (CCID) (39,40), which measured caregiver's communication with the patient about dying. The scale was developed in Israel by Dr. Yaacov Bachner, who approved the translation into Danish.

The scale was translated into Danish according to the recommendations by WHO (23) and adapted to a pre-loss setting. A sum score was calculated and dichotomized (low, high) with a cut point of 2. The ad hoc item *"How much information did you and your relative receive from the doctors about the future outlooks for your relative's illness?"* (too much, adequate, not enough, none) measured caregiver's perception of prognostic information and caregiver's *relation* (partner, adult child, other), *employment status* (working, compassionate leave, retired/unemployed) and *caregiving time* defined as the amount of hours spent on care (0-2, 3-8, 9-16, 17-24 hours/day) was measured.

#### *Pilot testing*

The questionnaires and cover letters were pilot-tested for readability, comprehension and acceptability in a vulnerable situation. Firstly, they were tested by 12 persons, who were not caregivers to terminally ill patients (colleagues at the Research Unit for General Practice, family and friends). Secondly, selected caregivers to terminally ill patients referred to The Palliative Team, Aarhus University Hospital, were asked by the staff to participate in a face-to-face pilot-test conducted by MKN. In total, seven persons from the target population agreed to test the questionnaire and participate in an interview. The pilot tests lead to a few changes in the order of the ad hoc questions and minor changes of wording. The phrasing of the cover letter and questionnaire was not considered offensive by the participants in the pilot test.

Six of the seven participants from the pilot-test of the target population were bereaved within two months and were contacted for pilot testing of the follow-up questionnaire. The palliative team staff kindly contacted additional caregivers resulting in a total of ten caregivers, who participated in the pilot testing of the follow-up questionnaire. The lay out, phrasing and the majority of included questions were similar to the baseline questionnaire. Only minor changes were made on follow-up questionnaire.

### Data collection procedure

A project-specific encrypted Access database was developed at the Research Unit for General Practice in collaboration with MKN.

All questionnaires had a unique serial number, which was linked with patient's CPR number in the database. On a weekly basis, CPR-numbers on newly registered patients were provided by a member of staff at the Danish Medicine Agency through a safe data connection (secure FTP-server) hosted by Aarhus University. The CPR-numbers were checked in the CRS regarding eligibility for contact. Exclusion criteria were: 1) the patient had already died, 2) the patient held publicly registered protection from receiving letters regarding research projects, 3) the patient was below the age of 18 and 4) patient had an invalid postal address. Postal addresses were obtained for the remaining patients and they were mailed a project invitation letter.

### *Baseline sampling*

The invitation letter contained study information for the patient, study information for the caregiver and a baseline questionnaire with a consent form for the caregiver. The patient was requested to forward the baseline questionnaire to their close relative. Patients and caregivers were encouraged to contact the project manager (MKN) if any question emerged. A reminder was send to non-responding patients after three weeks. Before sending this reminder, we checked that the patient had not been registered as deceased in the CRS.

If the patient did not wish to participate, we asked them to fill in three pre-printed reason for non-participation on the cover letter or write the reason for non-participation in full-text and return the cover letter. Pre-printed reasons for non-participation were: 1) No, I do not receive free prescription medicine due to serious illness, 2) I do not want to forward the questionnaire to one of my relatives and 3) I do not have a close relative to forward the questionnaire to. We expected a low response rate as the study population was in a vulnerable position and reasons for non-participation would provide an opportunity to estimate the generalizability of the cohort.

### *Follow-up sampling*

Serial numbers of completed questionnaires and non-participation letters were registered in the project database by MKN or an assistant. On the baseline questionnaire, participating caregivers were asked to provide their CPR-number, which was also registered in the database. To protect personal information on participants, the questionnaires were stored and subsequently archived in a safe locker.

Patients to participating caregivers were checked in the CRS for vital status six months after registration with drug reimbursement. Deceased patients were registered with a date of death. The date for sending out a follow-up questionnaire for the caregivers was generated in the database six months after the date of death. Four weeks after the follow-up questionnaire we mailed a reminder to non-responding caregivers.

### *Data entry*

The questionnaires were designed and processed in the computer program TeleForm Enterprise version 8.0 (Cardiff software Inc., San Marcos, CA, USA) for data capture by optical scanning. An assistant scanned all returned questionnaires and went through the registrations made by the program. When the assistant was in doubt of the answer or a more than one tick had been made in the response boxes, a blank answer was entered.

A previous study has documented the accuracy of the data processing using TeleForm (41). MKN performed a random check of 76 scanned questionnaires of 119 items. In three out of the 76 questionnaires a single item was incorrectly registered. Hence, the errors were few and no systematic misclassification was found. Data were transferred to the statistical program Stata (StataCorp LP, College Station, TX, USA) for analysis.

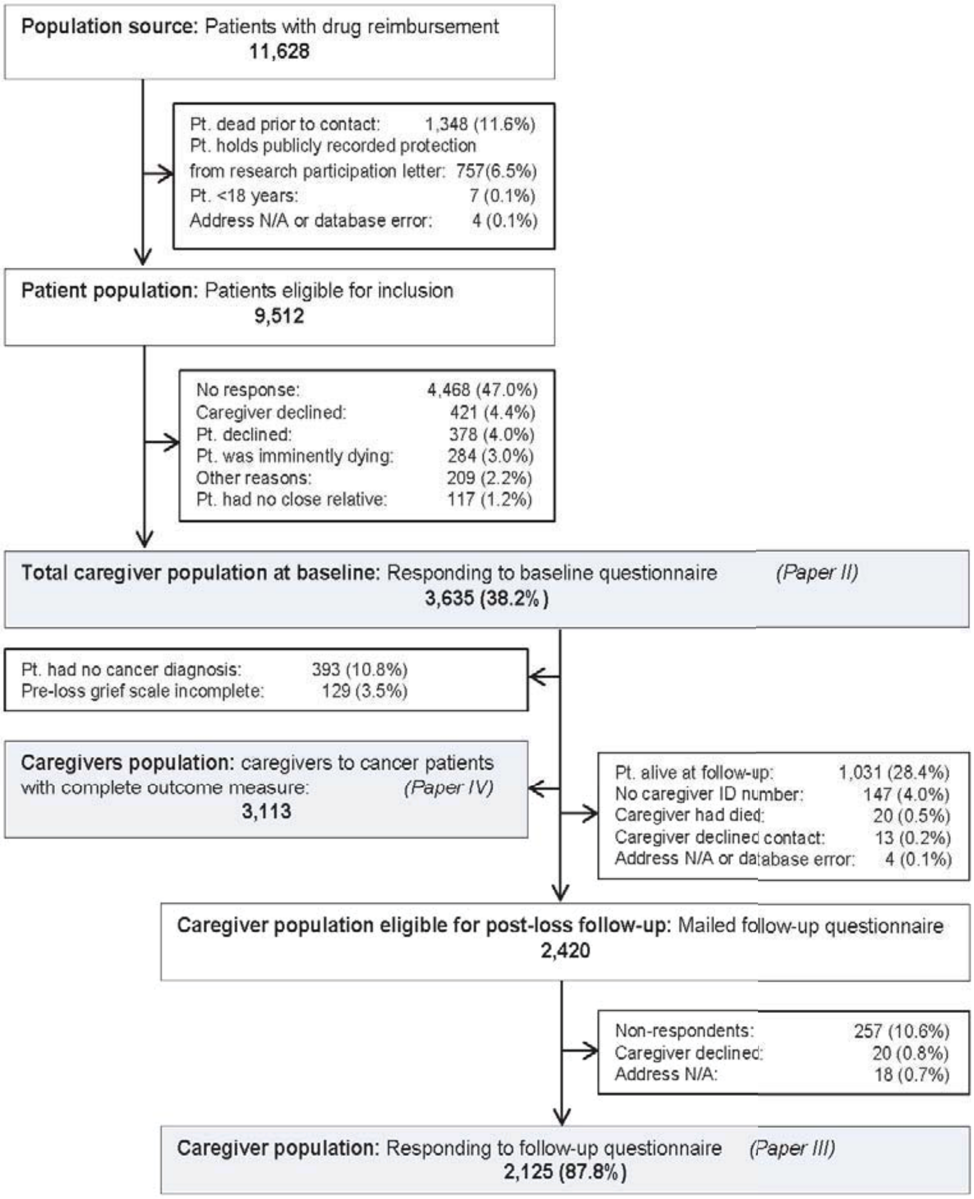
## The study population

The sampling procedure of the population-based Danish Caregiver Cohort 2012 gave rise to risk of selection of the study population in several steps as the procedure included sampling of both a patient population and a caregiver population. The flow of participants and non-participants in these populations is presented in this section.

### *The patient population*

In total, we received CPR-numbers on 11,628 patients granted drug reimbursement due to terminal illness from January to December 2012. Of these, 1,348 (11.6%) had already died before the registration in the CTR, 757 (6.5%) held recorded protection from receiving a researcher participation letter, 7 (0.1%) were below the age of 18 and for 4 (0.1%) a postal address was not available in the CRS or the address was not entered in the project database due to an error (Figure 2.2, on the following page). A cohort of 9,512 eligible patients was included during the study period. On average, 183 letters were sent to patients each week.

***Figure 2.2****. Flow diagram of participating caregivers of patients (pts.) formally registered with drug reimbursement due to terminal illness in 2012.*



The patients of responding caregivers were significantly more likely to be male, be young, have a partner, have a higher education, be non-immigrants, be suffering from cancer and have a longer survival time after receiving drug reimbursement than patients of non-responding caregivers. The median time to death of patients of non-participating relatives was 64 days after drug reimbursement and 93 days for patients with a participating caregiver (Table 2.2, on the following page).

***Table 2.1.*** *Patient characteristics and comparison between patients of responding and non-responding caregivers.*

| | All patients (N=9,512) | Patients with responding caregiver (n=3,635) | Patients with non-responding caregiver (n=5,877) |
|---|---|---|---|
| Age[a], years, mean (95% CI) | 71,6 (71-72) | 70.4 (70-71) | 72.4 (72-73)* |
| Sex | | | |
| Male | 4,825 (50.7) | 1,907 (52.4) | 2,918 (49.7)* |
| Female | 4,687 (49.3) | 1,730 (47.6) | 2,957 (50.3) |
| Cohabitation status | | | |
| Married or cohabiting | 5,309 (55.8) | 2,452 (67.5) | 2,857 (48.6)* |
| Living alone | 4,181 (44.0) | 1,175 (32.4) | 3,006 (51.2) |
| Missing data | 22 (0.2) | 8 (0.2) | 14 (0.2) |
| Educational level | | | |
| ≤10 years of education | 4,244 (44.6) | 1,464 (40.3) | 2,780 (47.3)** |
| >10 and ≤15 years of education | 3,613 (38.0) | 1,513 (41.6) | 2,100 (35.7) |
| >15 years of education | 1,198 (12.6) | 545 (15.0) | 653 (11.1) |
| Missing data[b] | 457 (4.8) | 113 (3.1) | 344 (5.9) |
| Ethnicity | | | |
| Not immigrant/descendant | 9,029 (94.9) | 3,495 (96.2) | 5,534 (94.2)* |
| Immigrant/descendant | 461 (4.9) | 132 (3.6) | 329 (5.6) |
| Missing data | 22 (0.2) | 8 (0.2) | 14 (0.2) |
| Urbanicity | | | |
| <4,999 inhabitants | 3,619 (38.1) | 1,433 (39.4) | 2,186 (37.2)** |
| 5,000-49,999 inhabitants | 2,938 (30.9) | 1,136 (31.3) | 1,802 (30.7) |
| >50,000 inhabitants | 2,922 (30.8) | 1,050 (28.9) | 1,872 (31.8) |
| Missing data | 33 (0.4) | 16 (0.4) | 17 (0.3) |
| Diagnoses | | | |
| Lung cancer | 2,140 (22.5) | 823 (22.6) | 1,317 (22.4)** |
| Colo-rectal cancer | 1,060 (11.1) | 428 (11.8) | 632 (10.8) |
| Breast cancer | 589 (6.2) | 226 (6.2) | 363 (6.2) |
| Prostate cancer | 550 (5.8) | 230 (6.3) | 320 (5.4) |
| Haematological cancer | 332 (3.5) | 124 (3.4) | 208 (3.5) |
| Other cancer | 3,597 (37.8) | 1,414 (38.9) | 2,183 (37.1) |
| Non-cancer[c] | 1,244 (13.1) | 390 (10.7) | 854 (14.5) |
| Patient survival time from drug reimbursement to death (median days (IQR))[d] | 64 (23-176) | 93 (41-216) | 47 (16-144)* |

Note: All variables as of 1 January 2012, unless otherwise stated
[*] P-value <0.001 using t-test indicating a significant difference in groups
[**] P-value <0.001 using chi-square-test a significant difference in groups
[a] At time of formal registration of drug reimbursement due to terminal illness
[b] Mostly elderly and immigrants. This is consistent with information from Statistics Denmark on the general Danish population [c]
[c] Non-cancer diagnoses were: COPD, heart failure, kidney failure, disseminated sclerosis, Parkinson's disease and dementia (listed according to incidence)
[d] Patients still alive as of 1 June 2014, i.e. end of follow-up (n=462) included

### *The caregiver population*

Of the 9,512 eligible patients we send a participation invitation letter, a total of 3,635 caregivers responded positively (38%), and 3,488 caregivers provided their CPR number, which was necessary for inclusion in the register-based analysis and the follow-up study. We received no response from 47% of the invited patients and their caregivers. Reported reasons for non-participation for the remaining 15% included that the patient or the caregiver declined to participate, the patient was imminently dying and the patient had no close relative (Figure 2.2). The predominant "other reasons" for exclusion was questionnaires filled in with the patient's CPR number (n=125). In some cases patients might have misunderstood the study and complete the questionnaire and in other cases caregivers might have completed the questionnaire and provided the patient's CPR number instead of their own by a mistake. However, to avoid bias we excluded these replies.

At the end of the follow-up period (six months after drug reimbursement), a large group of patients were still alive (28.4%) (Figure 2.2). Caregivers, who were bereaved later than six months after baseline, were excluded as we aimed to gather a homogenous cohort of caregivers to patients who were imminently dying. In total, 2,420 caregivers were invited to participate at follow-up six months after the death of the patient and 2,125 completed the follow-up questionnaire (88%).

### *Research participation in a vulnerable population*

Previously, a vulnerable population of bereaved caregivers was found to report positive experiences with participation in research studies although participation also caused distress (42). Similarly, a number of participants in this study contacted the project manager (MKN) by phone and indicated that it was helpful to systematically review their reactions and psychological distress before and after the patient's death, although completing the questionnaire was regarded emotional distressing. However, at baseline only a few patients and caregivers (n=20) contacted the project manager (MKN) by phone, e-mail or letter and found the study and questionnaire offensive.

## DATA ANALYSES

### *Confounding and effect modification*

Confounders can be defined as "confusion of effects" and effect modification refers to a situation in which an effect measure changes over values of other variables (43).

In the descriptive prevalence study (*Paper II*), confounding was not taken into account as no association between different factors was investigated. In this study, the situation for a partner, an adult child and caregivers with another personal relation to the patient might differ. Hence, we presented the studied prevalence in subgroups of spouses, adult children and other caregivers, respectively, to account for effect modification.

Prognostic research "*aims to predict as accurately as possible the probability or risk of future occurrence of a certain outcome as a function of multiple predictors*" (p. 127) (44). Thus, all investigated predictors (*Paper III*) were hypothesized to be equally important in the prognosis of the outcome. The pre-loss depressive symptoms were hypothesized to be a possible confounder for the associations between the other factors and outcomes based on prior studies. Thus, we stratified for depressive symptoms and investigated the association in the subgroup of caregivers without pre-loss depressive symptoms to establish whether the other factors were independent predictors of bereavement outcomes.

In the analysis of associations between socio-economic and palliative care-specific factors and severe PGS (*Paper IV*) we adjusted for age, gender and time to patient's death. These factors were hypothesized to be possible confounders of the investigated associations.

### *Statistical methods*

Variables were presented as proportions in case of categorical variables, as mean with a 95% confidence interval (CI) for continuous variables or median with an interquartile range (IQR) in case of data without normal distribution (*Paper I-IV*). Comparisons of prevalence were made using McNemar's test on paired proportions and presented by a p-value (*Paper III*).

The associations between independent variables and outcome variables were analysed using unadjusted and adjusted logistic regression and reported as an odds ratio (OR) with a 95% CI (*Paper III-IV*). Statistical analyses were performed using Stata version 13.1 or 14.0.

## RESEARCH APPROVALS AND ETHICS

According to the Act on Processing of Personal Data, researchers may carry out scientific studies of significant public importance on personal data without consent from the individual subject. The published results are required never to reveal the identity of the individuals or otherwise compromise the subjects (10). Under these conditions, the study was approved by the Danish Data Protection Agency (File no.: 2013-41-2603).

According to the Committee on Health Research Ethics of the Central Denmark Region, the Danish Act on Research Ethics Review of Health Research Projects (section 8(3) of Act No. 402 of 28 May 2003) did not apply to this study as questionnaire surveys do generally not require ethical clearance, which was confirmed in an e-mail on April 27th 2010 (request no. 48/2010).

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# CHAPTER 3:

## RESULTS IN SUMMARY

This Chapter contains the main results of the papers of the dissertation. A detailed presentation is provided in the individual papers.

## PRE-LOSS GRIEF SYMPTOMS AND PREPAREDNESS FOR DEATH (*PAPER I*)

In total, 34 papers were included (Figure 1, *Paper I*). Of these, 14 concerned grief during caregiving and 20 concerned preparedness for the impending death. Longitudinal designs were used in 20 studies, while 14 were cross-sectional studies. Of these longitudinal studies, seven assessed preparedness at different time points. In total, nine studies had a prospective study design with AG/pre-loss grief or preparedness assessments compared with bereavement outcome at follow-up.

### *Grief during caregiving*

In the included studies, grief during caregiving seemed to be encompassed in the term *pre-loss grief* or *pre-loss grief* symptoms (PGS). Severe PGS were in five of the seven longitudinal studies negatively associated with bereavement outcome and no association was found in the last two follow-up studies. Severe PGS were associated with complicated grief (1), high level of post-loss depressive symptoms (2,3) , high self-rated stress (2,3),  and post-loss avoidance (4) (Table 1, *Paper I*).

In the seven cross-sectional studies, caregivers with severe PGS were more likely to report previous or current depressive symptoms (5,6), previous stressful life events, pessimism (6), low levels of hope (7), use emotional (emotive) coping strategies (7), poorer health (8) and a stronger need for social support (6,9) (Table 1, *Paper I*). Female gender (7,8,10) and being a spouse (1,5,8,11) were factors associated with severe PLG symptoms, while studies investigating the association between pre-loss grief and age found diverging results.

### *Preparedness for the impending death*

Preparedness was measured by a single-item question regarding preparedness for death (12-15) or on the *Preparedness for Caregiving Scale* (16). In four studies, low preparedness for death was associated with complicated grief (12,15,17,18) and one of these studies (15) also found that low preparedness was associated with more depressive symptoms and anxiety. Furthermore, preparedness was assessed 4-5 years post-loss in three studies, which were based on the same cohort (13,14,19). In these studies, high preparedness was associated with long awareness time and higher levels of information on the impending death (14), low preparedness was in young caregivers associated with lack of grief resolution, anxiety, emotional numbness, and sleeping disorder (13). In pre-loss studies, high preparedness was associated with feelings of reward (20), hope and lower levels of anxiety (21) and low preparedness was associated with female gender (21). Nine follow-up studies were intervention studies that assessed the change in pre-loss preparedness over time or compared preparedness in different intervention groups.

## THE DANISH CAREGIVER COHORT 2012

### *The total cohort at baseline*

In total, 3,635 caregivers participated in the study at baseline. The mean age of caregivers was 61.2 years and the majority of caregivers were females (n=2,420). Most caregivers were partners of the patient (n=2,254), while 1,037 caregivers were adult children. In total, 927 caregivers (27%) had an educational level of less than 10 years and approximately one third of partners had a low educational level (Table 3.1).

***Table 3.1*** *Socio-economic characteristics of the caregiver cohort at baseline (n=3,635).*

| | | Relation to the patient[a] | | |
|---|---|---|---|---|
| | All caregivers | Partners n=2,254 (62.0%) | Children n=1,037 (28.5%) | Other relation n=269 (7.4%) |
| Age, years, mean (95%CI) | 61.2 (60.8-61.6) | 66.5 (66.1-66.9) | 49.9 (49.2-50.5) | 58.8 (57.2-60.3) |
| Age groups, years | | | | |
| <50 | 659 (18.1) | 152 (6.8) | 450 (43.4) | 57 (21.2) |
| 50-60 | 855 (23.5) | 377 (16.7) | 400 (38.6) | 77 (28.6) |
| 60-70 | 1,067 (29.4) | 848 (37.6) | 134 (12.9) | 83 (30.9) |
| > 70 | 907 (25.0) | 848 (37.6) | 9 (0.9) | 47 (17.5) |
| Missing data | 147 (4.0) | 29 (1.3) | 44 (4.2) | 5 (1.9) |
| Gender | | | | |
| Female | 2,420 (66.6) | 1,419 (63.0) | 787 (75.9) | 214 (79.5) |
| Male | 1,068 (29.4) | 806 (35.8) | 206 (19.9) | 50 (18.6) |
| Missing data | 147 (4.0) | 29 (1.3) | 44 (4.2) | 5 (1.9) |
| Cohabitation status | | | | |
| Married or cohabiting | 3,026 (83.3) | 2,128 (94.4) | 731 (70.5) | 163 (60.6) |
| Living alone | 451 (12.4) | 92 (4.1) | 258 (24.9) | 99 (36.8) |
| Missing data | 158 (4.4) | 34 (1.5) | 48 (4.6) | 7 (2.6) |
| Children living at home | | | | |
| Yes | 717 (19.7) | 198 (8.8) | 452 (43.6) | 67 (24.9) |
| No | 2,760 (75.9) | 2,022 (89.7) | 537 (51.8) | 195 (72.5) |
| Missing data | 158 (4.4) | 34 (1.5) | 48 (4.6) | 7 (2.6) |

.. continued on next page

| | | | | |
|---|---|---|---|---|
| Educational level | | | | |
| ≤10 years of education | 980 (27.0) | 741 (32.9) | 152 (14.7) | 85 (31.6) |
| >10 and ≤15 years of education | 1,651 (45.4) | 1,028 (45.6) | 511 (49.3) | 111 (41.3) |
| >15 years of education | 802 (22.1) | 416 (18.5) | 320 (30.8) | 63 (23.4) |
| Missing data | 202 (5.6) | 69 (3.0) | 54 (5.2) | 10 (3.7) |
| Gross income[b] | | | | |
| <20,000 euros/year | 921 (25.3) | 786 (34.9) | 86 (8.3) | 48 (17.8) |
| 20,000-34,999 euros/year | 922 (25.4) | 610 (27.1) | 216 (20.8) | 92 (34.2) |
| 35,000-50,000 euros/year | 880 (24.2) | 460 (20.4) | 347 (33.5) | 73 (27.2) |
| >50,000 euros/year | 760 (20.9) | 366 (16.2) | 343 (33.1) | 50 (18.6) |
| Missing data | 152 (4.2) | 32 (1.4) | 45 (4.3) | 6 (2.2) |
| Residency | | | | |
| Owned | 2,512 (69.1) | 1,644 (72.9) | 690 (66.5) | 175 (65.1) |
| Rented | 942 (25.9) | 565 (25.1) | 291 (28.1) | 83 (30.9) |
| Missing | 181 (5.0) | 45 (2.0) | 56 (5.4) | 11 (4.1) |
| Ethnicity | | | | |
| Not immigrant/ descendant | 3,389 (93.2) | 2,161 (95.9) | 966 (93.2) | 256 (95.2) |
| Immigrant/descendant | 88 (2.4) | 59 (2.6) | 23 (2.2) | 6 (2.2) |
| Missing data | 158 (4.4) | 34 (1.5) | 48 (4.6) | 7 (2.6) |
| Urbanicity | | | | |
| <4,999 inhabitants | 1,391 (38.3) | 924 (41.0) | 369 (35.6) | 96 (35.7) |
| 5,000-49,999 inhabitants | 1,041 (28.6) | 662 (29.4) | 303 (29.2) | 76 (28.3) |
| >50,000 inhabitants | 1,038 (28.6) | 629 (27.9) | 317 (30.6) | 88 (32.7) |
| Missing data | 165 (4.5) | 39 (1.7) | 48 (4.6) | 9 (3.3) |
| Number of chronic diseases[e] | | | | |
| 0 | 2,448 (67.4) | 1,483 (65.8) | 761 (73.4) | 200 (74.4) |
| 1-2 | 488 (13.4) | 372 (16.5) | 85 (8.2) | 30 (11.2) |
| >2 | 91 (2.5) | 72 (3.2) | 14 (1.4) | 5 (1.9) |
| Missing data | 608 (16.7) | 327 (14.5) | 177 (17.1) | 34 (12.6) |

Note: All variables as of 1 January 2012, unless otherwise stated

[a] Information on relation to the patient was missing for 75 caregivers (2.1%); these account for missing values in the relation variable

[b] For the year 2011

[e] Charlson Comorbidity Index (CCI) (22) based on hospital registered diagnoses during 2001-2011. Therefore, missing values include persons unregistered at the hospital.

### *The cohort at follow-up*

At follow-up, 2,125 caregivers participated. The participants had a mean age of 62 years, 70% were female and 64% were bereaved partners (Table 3.2). Patients had a mean age of 71 years, 91% were caregivers to a cancer patient and they had a median survival time from drug reimbursement of 58 days (IQR: 55-61).

***Table 3.2**. Characteristics of the caregiver cohort participating both at baseline and at follow-up (n=2,125).*

| | | |
|---|---|---|
| **Caregiver's socio-economic factors** | | |
| **Caregiver age, years**[a] (mean (95%CI)) | 62.0 | (61.5-62.5) |
| | | |
| **Caregiver gender** (n (%)) | | |
| Male | 638 | (30.0) |
| Female | 1,487 | (70.0) |
| | | |
| **Personal relation** (n (%)) | | |
| Partner | 1,360 | (64.0) |
| Adult child | 602 | (28.3) |
| Other | 163 | (7.7) |
| | | |
| **Cohabitation status** (n (%)) | | |
| Married or cohabiting | 1,865 | (87.9) |
| Living alone | 258 | (12.2) |
| | | |
| **Educational level** (n (%)) | | |
| <10 years | 558 | (26.6) |
| 10-15 years | 1,010 | (47.5) |
| >15 years | 530 | (24.9) |
| | | |
| **Patient-related factors** | | |
| **Patient age, years**[a] (mean (95% CI)) | 71.0 | (70.5-71.5) |
| | | |
| **Patient gender** (n (%)) | | |
| Male | 1,113 | (52.4) |
| Female | 1,012 | (47.6) |
| | | |
| **Diagnosis** (n (%)) | | |
| Lung cancer | 498 | (23.4) |
| Colo-rectal cancer | 236 | (11.1) |
| Breast cancer | 121 | (5.7) |
| Prostate cancer | 121 | (5.7) |
| Haematological cancer | 78 | (3.7) |
| Other cancer | 860 | (40.5) |
| No cancer[b] | 211 | (9.9) |
| | | |
| **Patient survival time in days** (median (IQI)) | 58 | (55-61) |

Note: All variables are of 1 January 2012, unless otherwise stated.

[a] Age at inclusion

[b] Non-cancer diagnoses included among others: COPD, heart failure, kidney failure, disseminated sclerosis, Parkinson's disease and dementia (listed according to incidence).

## CAREGIVER ASSESSMENTS DURING CAREGIVING (*PAPER II*)

In total, 32.4% of the caregivers reported pre-loss grief, depression or caregiver burden, and 20.5% had more than one of the mentioned conditions. The criteria for pre-loss grief were fulfilled for 15.5% of caregivers, moderate to severe depression symptoms was found in 16.1%, moderate to severe caregiver burden was experienced by 11.5% and 16.5% stated that they were not prepared. The SF-36 mean physical component score sum score was 50.2 (95% CI: 50.4-51.1), and the mean mental component score sum score was 41.0 (95% CI: 40.6-41.4) (Table 3.3).

Severe pre-loss grief symptoms were reported by 17.1% of partners and 11.3% of adult children. In total, 16.7% of partners and 15.0% of adult children had moderate to severe depressive symptoms, 10.6% of partners reported moderate to very severe caregiver burden, and 14.2% of adult children experienced caregiver burden (Table 3.3 on the following page).

*Table 3.3. Self-reported caregiver data on situational factors, distress and health*

| | | Relation to patient (n=3,560)[a] | | |
|---|---|---|---|---|
| | All caregivers (n=3,635) | Partners 2,254 (62.0%) | Adult children 1,037(28.5%) | Other relation 269 (7.4%) |
| Employment | | | | |
| Working | 1,252 (34.5) | 462 (20.5) | 661 (63.7) | 129 (48.0) |
| Compassionate/other leave | 557 (15.3) | 302 (13.4) | 226 (21.8) | 29 (10.8) |
| Not working (retired/unemployed) | 1,687 (46.4) | 1,442 (64.0) | 139 (13.4) | 104 (38.7) |
| Missing data | 139 (3.8) | 48 (2.1) | 11 (1.1) | 7 (2.6) |
| Caregiving time[b] | | | | |
| 0-2 hours/day | 1,121 (30.8) | 406 (18.0) | 551(53.1) | 145 (53.9) |
| 3-8 hours/day | 890 (24.5) | 521 (23.1) | 294 (28.4) | 65 (24.2) |
| 9-16 hours/day | 535 (14.7) | 426 (18.9) | 81 (7.8) | 18 (6.7) |
| 17-24 hours/day | 964 (26.5) | 816 (36.2) | 93 (9.0) | 34 (12.6) |
| Missing data | 125 (3.4) | 85 (3.8) | 18 (1.7) | 7 (2.6) |
| Practical care time[c] | | | | |
| 0-2 hours/day | 2,167 (59.6) | 1,120 (49.7) | 820 (79.1) | 195 (72.5) |
| 3-8 hours/day | 762 (21.0) | 594 (26.4) | 124 (12.0) | 31 (11.5) |
| 9-16 hours/day | 203 (5.6) | 156 (6.9) | 36 (3.5) | 8 (3.0) |
| 17-24 hours/day | 292 (8.0) | 248 (11.0) | 27 (2.6) | 10 (3.7) |
| Missing data | 211 (5.8) | 136 (6.0) | 30 (2.9) | 25 (9.3) |
| Preparedness | | | | |
| Low level | 598 (16.5) | 402 (17.8) | 150 (14.5) | 34 (12.6) |
| High level | 2,851 (78.4) | 1,702 (75.5) | 871 (84.0) | 227 (84.4) |
| Not relevant | 66 (1.8) | 55 (2.5) | 5 (0.5) | 5 (1.9) |
| Missing data | 120 (3.3) | 95 (4.2) | 11 (1.1) | 3 (1.1) |
| Communication | | | | |
| Low level | 295 (8.1) | 216 (9.6) | 58 (5.6) | 14 (5.2) |
| High level | 3,108 (85.5) | 1,860 (82.5) | 951 (91.7) | 243 (90.3) |
| Missing data | 232 (6.4) | 178 (7.9) | 28 (2.7) | 12 (4.5) |
| Pre-loss grief symptoms[d] | | | | |
| Sum score mean(95% CI) | 29.1 (28.8-29.4) | 30.7 (30.3-31.1) | 26.2 (25.6-26.8) | 26.6 (25.3-27.8) |
| Categorized: | | | | |
| No | 2,941 (80.9) | 1,765 (78.3) | 901 (86.9) | 228 (84.8) |
| Yes | 544 (15.0) | 386 (17.1) | 117 (11.3) | 28 (10.4) |
| Missing data | 150 (4.1) | 103 (4.6) | 19 (1.8) | 13 (4.8) |
| Depression[e] | | | | |
| Sum score mean (95% CI) | 12.2 (11.9-12.5) | 12.9 (12.5-13.3) | 11.3 (10.8-11.9) | 9.7 (8.7-10.7) |
| Categorized: | | | | |
| No | 2,141 (58.9) | 1,269 (56.3) | 659 (63.6) | 182 (67.7) |
| Mild | 692 (19.1) | 452 (20.0) | 188 (18.1) | 42 (15.6) |
| Moderate | 405 (11.1) | 261 (11.6) | 102 (9.8) | 29 (10.8) |
| Severe | 181 (5.0) | 115 (5.1) | 54 (5.2) | 7 (2.6) |
| Missing data | 216 (5.9) | 157 (7.0) | 34 (3.3) | 9 (3.3) |
| Caregiver burden | | | | |
| Sum score mean (95% CI) | 25.6 (25.2-26.0) | 25.5 (25.0-26.1) | 26.6 (25.7-27.4) | 22.5 (20.9-24.1) |
| Categorized | | | | |
| None or mild | 3,050 (83.9) | 1,901 (84.3) | 867 (83.6) | 227 (84.4) |
| Moderate | 377 (10.4) | 212 (9.4) | 134 (12.9) | 24 (8.9) |
| Severe | 40 (1.1) | 26 (1.2) | 13 (1.3) | 1 (0.4) |
| Missing data | 168 (4.6) | 115 (5.1) | 23 (2.2) | 17 (6.3) |
| Health[f] | | | | |
| Physical Component Score (PCS), mean (95%CI) | 50.2 (50.4-51.1) | 49.8 (49.3-50.2) | 53.0 (52.5-53.6) | 50.5 (49.2-51.7) |
| Mental Component Score (MCS), mean (95%CI) | 41.0 (40.6-41.4) | 40.4 (39.6-40.8) | 41.5 (40.6-42.3) | 44.8 (43.3-46.4) |
| Missing data | 168 (4.6) | 126 (5.6) | 19 (1.8) | 12 (4.5) |

[a] Information on relation to the patient was not obtained from the questionnaire for 75 caregivers (2.1%)

[b] The question was: '*How many hours did you spend per day (24 hours) on providing care for your relative?*'

[c] The question was: '*How many hours did you spend per day (24 hours) on practical care for your relative, e.g. bath, food, toilet visits, medication?'*

[d] Pre-loss version of the *Prolonged Grief-13 scale* (PG-13)

[e] *Beck's Depression Inventory-II* (BDI-II)

[f] The 36-item *Short Form Health Survey-36* (SF-36): 'component scores' are summary scores for physical and mental health, respectively

## SYMPTOMS OF GRIEF AND DEPRESSION - COMPARISON & PREDICTION (*PAPER III*)

### *Symptoms of grief and depression at baseline compared with follow-up*

In the follow-up cohort (n=2,125), 311 (15.1%) reported severe pre-loss grief symptoms and 312 caregivers (15.5%) experienced moderate to severe depressive symptoms at baseline (Table 3.4, on the following page). Of these, 146 (7.2%) reported both severe pre-loss grief symptoms *and* pre-loss depressive symptoms. At follow-up, CG was found in 152 (7.6%) of the caregivers and 234 (12.1%) had moderate to severe depressive symptoms. The proportion of caregivers with severe pre-loss grief symptoms was statistically significantly higher than the proportion of caregivers with CG without using the six months duration criterion (15.1% pre-loss compared to 8.4% post-loss ($p<0.001$)). The proportion of caregivers with moderate to severe depressive symptoms was higher at baseline compared to after the loss (15.5% vs. 12.1% ($p<0.001$)).

***Table 3.4.*** *Caregiver (n=2,125) reactions at baseline and complicated grief and depressive symptoms at six months post-loss follow-up.*

| | Baseline | | Follow-up | | |
|---|---|---|---|---|---|
| **Caregiver assessments** | | | | | |
| **Grief symptoms** (n (%)) | | | | | |
| Not severe grief symptoms/not complicated grief | 1,747 | (84.9) | 1,837 | (92.4) | |
| Complicated grief[a] | - | | 152 | (7.6) | |
| Severe grief symptoms[b] without duration criterion[c] | 311 | (15.1) | 167 | (8.4) | * |
| Severe grief symptoms[b] without duration criterion and changed item[d] | 238 | (11.6) | 154 | (7.7) | * |
| **Depressive symptoms**[e] (n (%)) | | | | | |
| None-mild | 1,708 | (84.5) | 1,754 | (87.9) | |
| Moderate-severe | 312 | (15.5) | 241 | (12.1) | * |
| **Caregiver burden**[f] (n (%)) | | | | | |
| None-mild | 1,811 | (88.5) | | | |
| Moderate-very severe | 236 | (11.5) | | | |
| **Preparedness for death**[g] (n (%)) | | | | | |
| Low | 263 | (12.9) | | | |
| High | 1,784 | (87.1) | | | |
| **Communication about dying**[h] (n (%)) | | | | | |
| Low | 164 | (8.1) | | | |
| High | 1,851 | (91.9) | | | |

Note: All variables are of 1 January 2012, unless otherwise stated.

*p<0.001 for the difference between proportions of caregiver with grief symptoms at baseline and at follow-up using McNemar's test

[a] *Prolonged Grief-13 scale* (PG-13).

[b] Pre-loss version of the *Prolonged Grief-13 scale* (PG-13).

[c] The PG-13 duration criterion assess whether symptoms have lasted for more than six months.

[d] The changed item in the pre-loss version of the PG-13 of this study was the item regarding "moving on". Due to the pre-loss context the item was changed to assess "hard to concentrate".

[e] *Beck's Depression Inventory-II* (BDI-II).

[f] *Burden Scale for Family Caregivers* (BSFC).

[g] Based on the item *"To which extent do you feel prepared that your relative might die from the illness?"*.

[h] *Couples' Communication about Illness and Death* (CCID).

### *Predictors of complicated grief and post-loss depressive symptoms*

Compared to other personal relations to the patient, being a spouse (adjusted OR=2.1, 95% CI; 1.2-3.7) and being a caregiver with less than 10 years of education (adjusted OR=2.0, 95% CI; 1.1-3.7) predicted CG (Table 3.5, on the following page). Age and gender were not independent predictors of CG. Post-loss depression was predicted by young age, female gender, spousal relation and low educational level (*Paper III*, Table 4). Severe pre-loss grief symptoms predicted CG (adjusted OR=3.9, 95% CI; 2.4-6.1) and post-loss depression (adjusted OR=1.8, 95% CI; 1.2-2.8). Pre-loss depressive symptoms were the dominating predictor of both CG (adjusted OR=5.6, 95% CI; 3.5-9.0) and post-loss depression (adjusted OR=11.3, 95% CI; 7.7-16.5). Specifically, 26% of the caregivers reporting severe pre-loss grief symptoms developed CG and 33% developed post-loss depression. Of caregivers reporting pre-loss depressive symptoms, 28% developed CG and 47% developed post-loss depression. Furthermore, low preparedness for the death was a predictor of post-loss depression (adjusted OR= 1.7, 95% CI; 1.1-2.6). In caregivers without pre-loss depressive symptoms (n=1,708), 4% developed CG and 6% post-loss depression and severe pre-loss grief symptoms were the key predictor of CG (adjusted OR=5.4, 95% CI; 2.8-10.4) and post-loss depression (adjusted OR=2.5, 95% CI; 1.3-4.7) in this subgroup.

*Table 3.5. Associations (ORs) between palliative caregiving-specific and socio-economic factors and complicated grief at six months post-loss follow-up in bereaved caregivers (n=1,989).*

| | Complicated grief[a] | | No complicated grief | | | |
|---|---|---|---|---|---|---|
| | N | (%) | n | (%) | OR (95%CI) | Adjusted OR* (95% CI) |
| **Age, years** | - | | - | | 1.0 (0.99-1.01) | 1.0 (0.97-1.00) |
| **Gender** | | | | | | |
| Male | 45 | (7.5) | 559 | (92.5) | ref | ref |
| Female | 107 | (7.7) | 1,278 | (92.3) | 1.04 (0.7-1.5) | 0.8 (0.5-1.2) |
| **Personal relation** | | | | | | |
| Partner | 121 | (9.7) | 1,133 | (90.4) | **2.4 (1.6-3.6)** | **2.2 (1.2-3.7)** |
| Adult child/other | 31 | (4.2) | 704 | (95.8) | ref | ref |
| **Educational level** | | | | | | |
| <10 years | 47 | (9.4) | 455 | (90.6) | **1.9 (1.2-3.2)** | **2.0 (1.1-3.7)** |
| 10-15 years | 77 | (8.1) | 876 | (91.9) | **1.6 (1.0-2.6)** | 1.4 (0.8-2.4) |
| >15 years | 26 | (5.1) | 483 | (94.9) | ref | ref |
| **Pre-loss depressive symptoms[b]** | | | | | | |
| None-mild | 61 | (3.8) | 1,559 | (96.2) | ref | ref |
| Moderate-severe | 80 | (27.6) | 210 | (72.4) | **9.7 (6.8-14.0)** | **5.6 (3.5-9.0)** |
| **Pre-loss grief symptoms[c]** | | | | | | |
| Mild | 73 | (4.4) | 1,577 | (95.6) | ref | ref |
| Severe | 76 | (26.2) | 214 | (73.8) | **7.7 (5.4-10.9)** | **3.8 (2.4-6.1)** |
| **Caregiver burden[d]** | | | | | | |
| None-mild | 105 | (6.1) | 1,604 | (93.9) | ref | ref |
| Moderate-very severe | 40 | (18.3) | 179 | (81.7) | **3.4 (2.3-5.1)** | 0.9 (0.5-1.6) |
| **Preparedness for death[e]** | | | | | | |
| High | 108 | (6.5) | 1,566 | (93.5) | ref | ref |
| Low | 37 | (15.0) | 210 | (85.0) | **2.6 (1.7-3.8)** | 1.5 (0.9-2.5) |
| **Communication about dying[f]** | | | | | | |
| High | 119 | (6.8) | 1,628 | (93.2) | ref | ref |
| Low | 21 | (13.6) | 133 | (86.4) | **2.2 (1.3-3.5)** | 0.8 (0.4-1.5) |

Note: Statistically significant results are stated in **bold.** *Mutually adjusted, [a]*Prolonged Grief-13 scale* (PG-13) (26), [b]*Beck's Depression Inventory-II* (BDI-II) (23), [c]Pre-loss version of the *Prolonged Grief-13 scale* (PG-13) (1,8), [d]*Burden Scale for Family Caregivers* (BSFC) (27,28), [e]Preparedness based on the item *"To which extent do you feel prepared that your relative might die from the illness?"* (12,13,15), [f]*Communication about illness and death* (CCID) (29,30).

## SEVERE PRE-LOSS GRIEF SYMPTOMS AND ASSOCIATED FACTORS (*PAPER IV*)

Caregivers reporting severe PGS were more likely to be females (Adjusted OR=1.6; 95% CI 1.2-2.1), partners (Adj. OR=2.5; 95% CI 1.8-3.4) and have a low educational level (Adj. OR=2.3; 95% CI 1.6-3.3) (Table 3.6, on the following page). Caregivers to younger patients were more likely to report severe PGS (Adj. OR=1.9; 95% CI 1.3-2.6) than caregivers to older patients. Severe PGS were associated with moderate to severe depressive symptoms (Adj. OR=10.4; 95% CI 7.7-13.9), caregiver burden (Adj. OR=8.6; 95% CI 6.3-11.8), a low level of communication about dying (Adj. OR=3.8 (95% CI: 2.7-5.4) and perception of prognostic information about the patient’s illness as ‘too much’ (Adj. OR=3.7; 95% CI 2.2-6.2) or ‘not enough’ (Adj. OR=1.7; 95% CI 1.2-2.5) compared to ‘adequate’ (Table 3.6, on the following page).

**Table 3.6.** Associations (ORs) of socio-economic factors, patient-related factors and caregiver assessments and severe pre-loss grief symptoms in a logistic regression model.

| | Pre-loss grief symptoms[a] | | | | | | Adj. | |
|---|---|---|---|---|---|---|---|---|
| | Severe | | Mild | | OR | 95% CI | OR* | 95% CI |
| **Caregiver's socio-economic factors** | n | % | N | % | | | | |
| Age[b], years | | | | | | | | |
| <55 | 153 | (33.0) | 821 | (32.4) | 1.1 | (0.9-1.4) | 0.9 | (0.5-1.5) |
| 55-65 | 131 | (28.2) | 671 | (26.5) | 1.1 | (0.9-1.4) | 1.0 | (0.7-1.4) |
| >65 | 180 | (38.8) | 1,043 | (41.1) | ref | | ref | |
| Gender | | | | | | | | |
| Female | 363 | (78.2) | 1,698 | (67.0) | 1.8 | (1.4-2.2) | 1.8 | (1.4-2.2) |
| Male | 101 | (21.8) | 837 | (33.0) | ref | | ref | |
| Relation | | | | | | | | |
| Partner/spouse | 346 | (72.8) | 1,597 | (61.8) | 1.7 | (1.3-2.1) | 2.6 | (2.0-3.4) |
| Adult child/other | 129 | (27.2) | 986 | (38.3) | ref | | ref | |
| Education | | | | | | | | |
| <10 years | 151 | (32.5) | 683 | (27.4) | 1.7 | (1.3-2.3) | 1.8 | (1.3-2.4) |
| 10-15 years | 228 | (49.1) | 1,208 | (48.4) | 1.5 | (1.1-1.9) | 1.5 | (1.2-2.0) |
| >15 years | 77 | (16.6) | 603 | (24.2) | ref | | ref | |
| **Caregiver assessments** | | | | | | | | |
| Pre-loss depressive symptoms[c] | | | | | | | | |
| None-mild | 193 | (42.5) | 2,267 | (89.8) | ref | | ref | |
| Moderate-severe | 263 | (57.5) | 257 | (10.2) | 12.0 | (9.6-15.1) | 12.4 | (9.8-15.7) |
| Caregiver burden[d] | | | | | | | | |
| None-mild | 297 | (62.9) | 2,385 | (93.2) | ref | | ref | |
| Moderate-very severe | 175 | (37.1) | 175 | (6.8) | 8.0 | (6.3-10.2) | 8.4 | (6.5-10.8) |
| Preparedness[e] | | | | | | | | |
| High | 316 | (66.9) | 2,124 | (84.5) | ref | | ref | |
| Low | 156 | (33.1) | 391 | (15.5) | 2.7 | (2.2-3.3) | 2.9 | (2.3-3.7) |
| Communication about dying[f] | | | | | | | | |
| High | 378 | (82.2) | 2,341 | (93.3) | ref | | ref | |
| Low | 82 | (17.8) | 167 | (6.7) | 3.0 | (2.3-4.0) | 3.3 | (2.5-4.5) |
| Prognostic information[g] | | | | | | | | |
| Too much | 34 | (7.5) | 71 | (2.9) | 3.0 | (1.9-4.5) | 2.9 | (1.9-4.5) |
| Adequate | 308 | (68.3) | 1,909 | (77.5) | ref | | ref | |
| Not enough | 87 | (19.3) | 331 | (13.4) | 1.6 | (1.2-2.1) | 1.7 | (1.3-2.2) |
| No | 22 | (4.9) | 151 | (6.1) | 0.9 | (0.6-1.4) | 0.9 | (0.5-1.4) |

Note: All variables as of 1 January 2012. *Adjusted for caregivers' age and gender and survival time from inclusion. [a] Pre-loss version of the *Prolonged Grief-13 scale* (PG-13) (1,11,26).[b] Age at inclusion. [c]*Beck's Depression Inventory-II* (BDI-II) (23).[d] *Burden Scale for Family Caregivers* (BSFC) (27,28).[e]Preparedness based on the item *"To which extent do you feel prepared for that your relative might die from the illness?"*.[f] *Couples' Communication about illness and death* (CCID) (30).[g] Information from physician about the patients' risk of dying from the illness.

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# CHAPTER 4:

## DISCUSSION OF METHODS

The study design, study conduct and the data analysis is important for the interpretation of findings and estimates of a study (1). Accuracy in estimates is a principal factor, which contains the key components validity and precision (1). Studies of high validity and high precision oppose studies with systematic errors (predominantly bias due to selection or data misclassification) and random errors (1). For the application of findings in clinical care it is important to consider the generalizability. In this Chapter, the applied study designs, selection bias, data quality, validity and precision in analysis are discussed. Finally, the generalizability of the results is addressed.

## THE SYSTEMATIC REVIEW

In this section, we present considerations of study design, risks of selection bias, bias in individual studies and between studies, validity and comparability of measures.

### *Study design*

The method of the systematic review (*Paper I*) aims to combine results from existing studies "*in the hopes of identifying patterns among study results, source of disagreement among those studies, or other interesting relationships that may come to light in the context of multiple studies* (p. 652) (1). The review study of this dissertation achieved to reveal a pattern of the effect of severe pre-loss grief and low preparedness on bereavement outcome and outlined shortcomings regarding definitions and measurements of the factors in the existing literature. Hence, from the systematic review, we aimed to identify "*frontiers"* for new research (2). A meta-analysis includes a summarization of study findings and may have reduced uncertainty in case of conflicting results (2). We aimed to investigate two predefined exposures and report different bereavement outcomes. Thus, it was not possible to make a summary estimate of findings.

The systematic review was conducted according to the PRISMA statement (3). This approach provided a transparent systematic review and complete reporting of the method, which may enable other researcher to repeat the method.

### Risk of bias

The risk of selection bias in the literature search was reduced by using a systematic approach based on the PRISMA statement (3). Nevertheless, the search was limited to include English-language peer-reviewed research papers. This approach might have excluded important knowledge on the subject presented in, for example book chapters, abstracts, non-English scientific articles or non-published work. Still, inclusion of peer-reviewed papers is likely to ensure a high standard of included studies.

### *Bias in the individual studies and between studies*

The included studies were diverse regarding sample size, study design and purpose of the study and bias may be present in the individual study. For instance, eight of the studies assessed the exposures (AG/preparedness) retrospectively, which might have caused recall bias if bereaved caregivers with adverse outcomes (bereavement complications) were prone to explain their present psychological distress at by low preparedness.

Before comparison of studies, we conducted quality assessment of the study design. This assessment enabled us to rank the studies before the data synthesis and studies with the most rigorous designs received the heighest weight. Still, in half of the included studies, assessments were exclusively measured before the loss, which eliminated the possibility to assess bereavement outcomes. Hence, in important conclusion from the systematic review was that prospective studies are needed and the existing literature should be interpreted with caution.

### *Validity and comparability of measures*

The primary variables of interest were the exposure variables AG/pre-loss grief and preparedness. In the synthesis, the different definitions and measurements of AG and preparedness were cautiously taken into consideration to ensure comparability between studies. The included studies used a range of different AG/pre-loss grief and preparedness measurement tools. Some of these had not undergone psychometric testing. This gave rise to challenges in regard to comparison and synthesis of outcome. Therefore, we analysed definitions and measurement tools before synthesis of outcome and no study was excluded from the data synthesis due to inconsistency of definition or measurement tool.

### *Summing up on the systematic review*

We conducted a systematic review according to the PRISMA statement and fulfilled our purpose to establish the association between AG/preparedness and bereavement outcome. Still, some of the included studies had a low sample size, low quality assessment and the findings were difficult to include in the data synthesis. High quality of studies included in systematic review is crucial (4) and the systematic review may have benefitted from a more restrictive inclusion criteria regarding study design as the data synthesis might have been less comprehensive. Nevertheless, the findings of the review highlighted gaps in current knowledge, which we aimed to close or diminish through knowledge from the Danish Caregiver Cohort 2012 study (*Papers II-IV*).

## THE DANISH CAREGIVER COHORT STUDY

Systematic identification of a population-based cohort may increase the validity and generalizability of findings (5). We systematically identified a large nation-wide population of patients with terminal illness to sample the target population of caregivers. The advantages of the study were challenged by a low response rate at baseline, which could cause selection bias. In this section, issues regarding study designs, selection bias, information bias, data quality and validity are addressed. Finally, a discussion of the generalizability is provided.

### Study design

#### *The cross-sectional study design*

Cross-sectional studies are appropriate for measuring the prevalence of a factor of interest or assess the relation between prevalence and possible exposures (5). The prevalence of factors related to caregiving assessed at baseline (*Paper II*) was investigated in a cross-sectional study design, which may be called a *prevalence study* (1). In a prevalence study, the risk of length-biased sampling must be considered (1). This bias is related to the duration of the disease/factor of interest; long duration of the investigated factor may cause an overrepresentation of cases, while short duration may cause an underrepresentation in a cross-sectional design, which provides only a 'snapshot' at a specific point in time (5). Factors investigated in the studies of this dissertation were hypothesized to be persistent over the period of caregiving from drug reimbursement to death. Still, caregivers were assessed at different time points in the terminal illness trajectory due to the data collection method. This might have influenced the prevalence. For instance, caregivers may report more depressive symptoms close to patient's death (6), which may affect the prevalence. Furthermore, the assessment of preparedness for the impending death may differ according to the proximity to patient's death. Hence, length-bias sampling might play a role for caregiver assessments and patient's median survival time may be necessary to take into account in the interpretation of estimates.

The analytic cross-sectional study (*Paper IV*) analysed factors associated with severe pre-loss grief symptoms at baseline. Due to the cross-sectional design no causal inference can be made (5). Yet, the studied background variables such as age (birth date) and gender were not considered dynamic as they do not change over time. Thus, for these factors the cross-sectional design may be as informative as a longitudinal design (5). The cross-sectional design was a disadvantage for the interpretation of the association between severe PGS and caregiver reactions. For instance, the strong association of severe pre-loss grief symptoms with high caregiver burden in this study provides no insight to whether severe pre-loss grief symptoms may cause high caregiver burden or vice versa. A longitudinal study design with assessment of the factors at different time points during caregiving would be appropriate for the investigation of the causal inference between the factors. However, this was not the scope of this dissertation.

#### *The longitudinal cohort study design*

A central feature of a prospective study design is the order in time of recording exposure information before the occurrence of outcome (1). Recall bias is information bias that may occur in a cross-sectional study when study participants who report the investigated outcome recall the exposures more accurately than participants who do not report the outcome.  In a prospective longitudinal study design, we analysed predictors of adverse bereavement outcomes (*Paper III)* and recall bias was therefore avoided. This study design allowed us to interfere on causal relations for instance regarding the finding that severe PLG was linked with higher risk of CG and post-loss depressive symptoms (*Paper III*). Furthermore, the assessment of preparedness for the death before the patient's death carried out in our study has only been done in a single prior study to caregivers to nursing home residents (7). Hence, new knowledge was provided and recall bias was avoided, although the assessment of participants at different time point before in the patient's terminal illness trajectory should be taken into account in the interpretation of the findings.

### Selection bias

*"Selection bias is a systematic error in a study that stems from the procedures used to select subjects and from factors that influence study participation"* (p. 126) (5). We recruited a population-based caregiver cohort and obtained a low recruitment rate of 38% caregivers of the total cohort of eligible patients, who were mailed a study information letter. A low recruitment rate may only induce bias if exposure or outcome levels differ between participants and non-participants (5). Because the outcomes of the longitudinal study (*Paper III*) had not yet occurred at baseline, the internal comparison

between exposures and outcomes may be performed without bias due selection in the recruitment process (8). Loss to follow-up may constitute a more important risk of bias. Considerations of the selection of participants during recruitment are crucial for the assessment of the generalizability the study findings. Likewise, the generalizability of the cross-sectional studies (*Paper II* and *IV*) would be affected by selection bias and the prevalence would be over- or underestimated according to the selection in the study population.

In this section, the sampling procedure of caregivers through patients with drug reimbursement will be discussed as it might give rise to selection bias in four steps; identification of participants, patient's eligibility before contact, non-participation by patients and caregivers at baseline and loss to follow-up.

### *Identification of participants*

The systematic sampling of caregivers through a nation-wide register markedly reduced the risk of systematic errors due to sampling through health professionals. Palliative care and bereavement research studies often use recruitment of participants through health professional, which might induce selection because the recruiting health professionals might only be in contact with a subgroup of the target population. Furthermore, systematic sampling of non-distressed caregivers might take place if the recruiting health professionals protect distressed caregivers from participitation. Recruitment through health professional have resulted in higher participation rates of 77-83% in a Danish palliative care setting (9,10). Yet, other studies conducted in a vulnerable population of caregivers to terminally ill patients had comparable moderate response rates of 30-47% (11,12). Hence, research participation may be challenged in a vulnerable study population such as caregivers to terminally ill patients.

### *Eligibility of the patient population*

Before sending out the questionnaire a number of patients (n=1,348 (11.6%)) had died and were not eligible. As caregiver's psychological distress may be higher close to death (6), exclusion of these patients may have caused underestimation of the distress experienced by the caregivers.

### *Non-participation at baseline*

The largest group of non-respondents (n=4,468) stated no reason for non-participation, while a smaller group (n=1,409) of non-respondents reported a reason for non-participation. The reported main reasons for non-participation were that patient (n=421) or caregiver (n=378) did not wish to participate, the patient was imminently dying (n=284), lack of caregiver energy (n=122) and irrelevance as no symptoms of terminal illness were present (n=139) (Figure 2.2, page 45). That the patient was imminently dying or the caregiver lacked energy might have caused underestimation of distress, while no patient symptoms might have cause overestimation. This information point to diverging reasons for non-participation. Systematic selection of participating caregivers can not be ruled out, although the reasons seem to have opposite effects on study outcomes.

It remains unclear whether the reasons reported by this smaller group of non-participants (n=1,409) is applicable to the larger group of non-participants (n=4,468), who gave no reason for non-participation. To address the risk of selection bias in the latter group of non-participants, we compared register-based data on patients of participating caregivers with patients to non-participating caregivers. Patients to participants had a higher educational level and were younger than patients with no responding caregiver (Table 2.1, page 46). This might have caused an underestimation of psychological distress due to high education (13), while the younger patient age might have caused an overestimation of distress compared to non-participating caregivers. The median survival time from formal registration of drug reimbursement to death was 93 days for patients with responding caregivers compared to 47 days for patients with non-responding caregivers. This indicates that only a minority of the patients of responding caregivers are in the late terminal phase, which is the period when most caregivers tend to report depressive symptoms (6) potentially leading to a lower level of psychological distress. In sum, the direction of possible selection bias was found to be diverging and no major systematic selection bias seemed to be present.

### *Loss to follow-up*

A response rate above 70-75% (5) seems to be considered high. At follow-up, 88% of caregivers eligible for follow-up participated. Hence, loss to follow-up was low, which improved the quality of the internal comparison in the follow-up cohort (*Paper III and IV*).

Still, a large group of caregivers (33% of participants at baseline) were not eligible to follow-up because the patient had not died at the end of the six month follow-up period. As caregivers to these patients were not contacted, they were not accounted for in the response rate. Still, we analysed potential selection bias by comparing the total cohort with the subgroup comprising the follow-up cohort. The comparison of prevalence rates in caregiver assessments revealed a slightly lower level of severe PGS, same levels of caregiver burden, slightly more depressive symptoms and a higher proportion of low preparedness in the total baseline cohort. Participant's mean age, gender, personal relation and socio-economic factors were comparable in the baseline cohort (Table 3.1, page 57) and the follow-up cohort (Table 3.2, page 59).

Hence, no major systematic selection was found, but the follow-up cohort (*Paper III*) may represent caregivers to patients in the late terminal illness trajectory.

### Information bias and data quality

Information bias may arise when the information from collected data contains errors (1). Misclassification in different types of variables (exposure, confounder, outcome) can cause such errors. Misclassification can be non-differential which tends to produce a bias towards the null, while differential misclassification can either over- or underestimate the true association (1). Data from the Danish Caregiver Cohort 2012 was obtained partly from registers (for sampling and background variables) and partly from questionnaires (for outcome measures and caregiver assessments).

#### *Register-based data*

Patients registered with drug reimbursement due to terminal illness were expected to be correctly classified in the *CTR* as registrations were made by a physician, who known the patient and the illness trajectory and the patient needed the registration to receive medication free of charge. The information letter was returned by eight patients, who indicated that they did not receive drug reimbursement (Figure 2.2, page 45: "other reasons"). The patient might not have understood the information regarding drug reimbursement and it remains uncertain whether they were truly misclassified. However, the number of patients, who reported this potential misclassification was very low (8 of 9,512 invited patients) and is unlikely to have caused information bias.

Information on background variables was obtained from registers at Statistics Denmark including the *DCR* and the *DNPR*. The registers are being updated continuously and do not rely on the recall of the included population, which limits these sources of information bias (14). Furthermore, these registers have been shown to have completeness and validity (14-16). Thus, the risk of information bias is estimated to be very low.

### *Questionnaire data*

The systematic data entry process ensured low number of misclassification of caregiver responses (17). For each questionnaire variable, the number of missing data was explored. For the utilized scales, a single missing item response resulted in registration of the total scale as missing. The only exception was the BSFC scale, where two missing items of the 28 items in the scale could be missing according to the manual (9,18). In general, missing data was found in less than 6.4% of responses at baseline (the CCID-scale measuring communication about dying and prognostic information) and at follow-up (the PG-13 measuring complicated grief) (Table 4.1). Information bias due to these low rates of missing data was regarded unlikely.

***Table 4.1***. *Numbers of missing data in variables obtained from questionnaires.*

| | Post-loss | | Pre-loss | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | PG-13 | BDI-II | PL-PG | BDI-II | BSFC | Preparedness | CCID | Progn. Info | Relation | Education |
| | | | | | n (%) | | | | | |
| Total cohort, (n=3,635) | - | - | 150 (4.1) | 216 (5.9) | 168 (4.6) | 186 (5.1) | 232 (6.4) | 231 (6.4) | 27 (0.7) | 202 (5.6) |
| Follow-up cohort, (n=2,125) | 136 (6.4) | 130 (6.1) | 67 (3.2) | 105 (4.9) | 78 (3.7) | 78 (3.7) | 110 (5.2) | 110 (5.2) | 0 | 27 (1.3) |

PG-13: Prolonged Grief-13, BDI-II: Beck Depression Inventory-II, PL-PG: pre-loss version of the PG-13, BSFC: Burden Scale for Family Caregivers, CCID: Couple's Communication about Illness and Death, Progn. Info: perceived information about the patient's prognosis,

We used psychometrically tested measurement tools published in international journals whenever possible. Still, the study was limited by a lack of validation of the tools used to measure pre-loss grief (pre-loss version of the PG-13) and preparedness for death (single-item question).

A pre-loss version of the PG-13 scale has been used in few prior studies and similar sum scoring and criteria fulfillment was applied in this study (*Paper II-IV*), which ensured a high comparability. However, the fact that we changed an item in the pre-loss version of PG-13 (see *Chapter 2*, page 41) might impact the comparability. We compared the fulfillment of the severe pre-loss grief symptoms criteria without this item and found a prevalence of 11.6%, which was 3.5% lower than the prevalence of 15.1% based on all the pre-loss PG-items (Table 3.4, page 63). When this specific item also was omitted in the PG-13 scale post-loss we found that 7.7% fulfilled the CG criteria compared to 7.6% on the total scale. Hence, the prevalence of severe PGS might have been lower, if we had not changed the item, although the prevalence of severe grief symptoms remained statistically significantly higher pre-loss than post-loss.

Preparedness was measured with a single-item question based on a previously used question (19-21) and the wording was changed into a pre-loss context. In face-to-face pilot testing (n=7 bereaved caregivers) it showed good face validity, but no further testing was performed. Another tool such as the 8-item psychometrically tested '*Preparedness for Caregiving Scale*' (PCS) (22) may have added important knowledge on the different dimensions of preparedness as the used single-item question is only capable of providing an overall picture of caregivers' preparedness. However, the PCS does not address the impending death directly, and the single-item question was therefore regarded as the most appropriate of the available measurement tools.

### Data analyses

Variables associated with caregiver's grief symptoms during caregiving (*Paper IV*) and their grief and depressive symptoms during bereavement (*Paper III*) were interpreted in the light of a theoretical framework to provide an overview of the multifactorial outcomes, which will be addressed in the discussion of main results. However, other unmeasured factors may also play an important role for caregiver's bereavement outcomes. This issue and statistical analysis and precision will be discussed next.

#### *Statistical analyses*

Statistical analyses are used to control for confounding and assess variability in the measured estimates (5). In the baseline prevalence study (*Paper II*), we hypothesized based on prior studies that psychological distress and other caregiver reactions may differ according to personal relation to the patient. Therefore, we presented the prevalence of factors in strata of the factor personal relation in order to account for differences in effects in strata. We found that for instance, partners had higher levels of severe PGS and depressive symptoms compared to adult children, which provides important knowledge for clinical care. However, stratification for other factors such as gender or age was also taken into consideration, but personal relation was found to play a central role in the existing literature.

Control for confounding by stratification is effective and straight-forward (5). In *Paper III*, we analyze a subgroup of caregivers, who were a priori hypothesized to differ from the total cohort; pre-loss depressive symptoms was found to be a key factor for the development of adverse bereavement outcome in prior studies. Thus, by stratification for pre-loss depressive symptoms we toke the possible confounding effect of this factors into account and, thereby, we achieved establish the role of severe PGS as an independent predictor of CG and post-loss depressive symptoms. In *Paper IV,* we adjusted for the possible confounders: age and gender. However, residual confounding may be present in the analysis. For instance, pre-loss depressive symptoms might play a role as a confounder in Paper II and IV, but was not controlled for.

For the analyses in *Paper II-IV*, residual bias might be present in terms of unmeasured factors related to the illness e.g. the patient's symptom severity, the context of caregiving e.g. support from health professionals or the caregiver e.g. social support from the network. Hence, these unmeasured factors are important to take into consideration in the interpretation of the finding.

The large sample size of the cohort ensured high statistical precision with small confidence intervals indicating low variability ensuring low risk of random errors (5). In the prediction study (*Paper III*), the size of the cohort enabled mutually adjustment for the investigated predictor variables. Logistic regression was used in the univariable and multivariable analyses (*Paper III-IV*), because outcome measures were dichotomized sum scores (depressive symptoms) or categorizations based on criteria (complicated grief and pre-loss grief symptoms) as dichotomization may improve the usability of the results in clinical care.

### Generalizability

Population-based studies with a high number of participating caregivers to terminally ill patients are scarce in the existing literature (23,24). A nationwide sample of approx. 11,000 terminally ill patients with drug reimbursement status during 2012 formed the basis for recruitment of the study population of caregivers. In Denmark, nearly 50,000 patients die from illness-related death each year (25) and due to multiple causes of death these patients may comprise a heterogenous group. Caregiver to patients granted drug reimbursement due to terminal illness might comprise a selected group of all caregivers to dying patients as patients registered with drug reimbursement primarily are cancer patients. The burden and psychological distress might differ in caregiver to patients suffering from different diseases. The systematic review of this dissertation (Paper I), point to a similar pattern for the associations between severe PGS and preparedness with adverse bereavement outcome, which supports the generalizability of this study. Furthermore, because of their need for financial remuneration, patients with drug reimbursement might be more likely to have a lower socio-economic position than patients without drug reimbursement, although no Danish study has investigated this association. Lower socio-economic position has been associated with a higher level of psychological distress, which might have caused higher levels of psychological distress in our study. Still, this possible selection might be leveled out by the higher socio-economic position of patients to participating caregivers compared to non-participating caregivers. In addition, formal registration with drug reimbursement due to terminal illness may also provide a social safety-net and an opportunity for communication with health professionals regarding the patient's illness stage, which may reduce caregiver's distress. Hence, a range of known and unknown factors seem to influence the selection patterns and the generalizability of the findings. Overall, the study is considered generalizable to caregivers to terminally ill patients in a Danish setting. It may also be generalizable in international settings in which caregiver contexts are comparable, for instance, in the level of support from the health care system. In addition, the result might be restricted to caregivers of a patient with a survival time of less than six months.

#### *Summing in on the Danish Caregiver Cohort study*

Using systematic sampling from a nationwide population of patients to recruit participating caregiver for the Danish Caregiver Cohort 2012 study, we achieved to study a caregiver population. Strengths were low attrition among caregivers eligible for follow-up, the low level of missing data from questionnaires and the register-based data retrieved from nationwide registries with high completeness. Furthermore, the large sample-size allowed for precision in the estimates and adjusted analyses. No unidirectional systematic selection bias was found, although several factors impacted the selection of participants. The results were considered generalizable to caregivers to terminally ill patients in the general population. However, results may be restricted to caregivers of patients with a survival time of a couple of months.

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# CHAPTER 5:

## DISCUSSION OF RESULTS

The findings from the four papers (Paper I-IV) added new knowledge to the gaps described in the four aims of this dissertation. In this Chapter, the findings are discussed for each aim of the dissertation and a brief interpretation in the light of the IRFF of some of the results is provided at the end of the section.

## PRE-LOSS GRIEF SYMPTOMS AND PREPAREDNESS FOR DEATH (AIM 1)

The findings of the systematic review (*Paper I*) address aim 1) as high level of grief during caregiving and low preparedness were associated with adverse bereavement outcome, mainly in terms of CG.

### *The role of grief symptoms before the death*

High levels of pre-loss grief symptoms were found to be a risk factor for bereavement outcome, which seriously contrasts with the original hypothesis of AG (1). Originally, AG was assumed to alleviate caregiver's grief during bereavement and facilitate adjustment to the loss because emotional bonds were relinquished during before the loss (1). The concept of AG as an emotional reaction to alleviate grief beforehand has been gravely questioned by other researchers (2-4), which is supported by finding from this systematic review literature.

Grief during caregiving seems to be a complex process, which has been suggested to be 'a reaction to a multiple loss situation' (2) induced in caregivers to patients with a terminal illness. The type of loss (child, partner, parent) and the closeness of the relationship to the patient may play an important role for the reaction to these losses. Instead of relinquishing bonds as hypothesized in the original idea of AG, reorganization of bonds between the caregiver and the patient has also been regarded important for psychological adjustment, and the ability to make this adaptation may be connected with caregiver's attachment style and coping (5). Hence, severe levels of grief in caregivers may be associated with inefficient coping. One of the included studies found that a high level of AG was associated with use of an emotional coping strategy (6). Furthermore, coping style was suggested to be a mediator of grief reactions both before and after the loss (6). The importance of coping style and flexible use of coping styles on grief reactions are core aspects of the DPM. In this model, the coping-derived *oscillation* between loss- and restoration-oriented stressor is crucial for caregiver adjustment (7). Hence, severe PGS may occur because of multiple losses during caregiving. It is linked with the relation to the patient and coping style and was in existing literature found to be a complex risk factor for adverse bereavement outcome, particularly CG.

### *The role of preparedness for the death*

Low preparedness for death was found to be associated with complicated grief, post-loss depression and post-loss anxiety. To report high preparedness, the caregiver's preparation has to include cognitive, behavioral and emotional matters (8). Dealing with financial arrangements and conflict solving may prepare cognitively and behavioral and confrontation with the losses inflicted by the terminal illness may prepare emotionally. This may be interpreted as *oscillation* between loss- and restorations-oriented stressors in line with the DPM (7).

In sum, severe PGS and low preparedness were in prior studies found to be a risk factor of adverse bereavement outcome. Still, studies on the effect of severe PGS and low preparedness were few and longitudinal studies seemed to be lacking. In the light of contemporary grief theory and the IRFF, both grief during caregiving and preparedness for the death may be interpreted as complex risk factors for adverse bereavement outcome focusing on different aspects of the caregiver's situation. The terminology of grief symptoms before the patients' death may benefit from a shift away from the use of AG and towards loss and grief during caregiving.

## SYMPTOMS OF SEVERE PRE-LOSS GRIEF AND DEPRESSION AND CAREGIVER BURDEN (AIM 2)

### *Symptoms of pre-loss grief and depression*

The criteria for severe PGS were met for 15% participants and severe PGS were more frequent in partners than in adult children. In a small study conducted in a specialized palliative care setting, the prevalence of pre-loss grief among 301 caregivers was 14.9% (9), which is consistent with the findings of the present larger study in a general population setting. However, we changed an item in the PGS measurement tool, which might have caused a slight overestimation of the prevalence of PGS. Still, our findings establish severe PGS as a condition found in a broad cohort of caregivers and underline the importance of focusing on PGS.

Overall, 16% of caregivers reported symptoms indicative of depression, while the depression prevalence has formerly been reported to be only 3-4% in the general Danish population (10). Caregivers of dying patients have in prior studies reported a depression prevalence of 26-57% (11,12), which considerably exceeds the level found in the present cohort. Our caregiver cohort was systematically sampled through terminally ill patients, regardless of their contact with specialized palliative care, and patients were in different stages of their terminal illness as about half of the patients were still alive three months after inclusion. Therefore, we estimate that our results reflect the level of depressive symptoms better in a general population, which comprises caregivers of patients ranging from early to late stages of the palliative trajectory.

### *Preparedness for the death and caregiver burden*

We found a prevalence of low preparedness of 17%. A previous Swedish study of 691 widowers retrospectively assessed the preparedness in caregivers and found low preparedness in 16% of the participants (13). Preparedness was assessed pre-loss in our large-scale population representative of the general population and the significant level of low preparedness underlines the need for addressing preparedness in caregivers to terminally ill patients.

High caregiver burden was reported by 11%. This level was consistent with findings of previous smaller studies on caregiver burden measured with the same scale (14,15). In prior studies, caregiver burden has been associated with younger age, being a wife (compared to being a daughter) (16), female sex, living with the patient, a high number of caregiving hours and inability to continue regular employment (17). Our findings differ partly from these studies as adult children of terminally ill patients seemed to have the highest level of caregiver burden. The large subgroup of adult children (n=1,037) were predominantly female (3/4. Many had children living at home (43.6%), most attended a full-time job (63.7%) and 21.8% had compassionate leave. Although only 1/5 of the adult children had compassionate leave, almost half spent at least three hours per day providing care for their ill parent. Taking care of an ill parent while working full-time and attending one's own family may be stressful and demanding. More adult children than partners reported low preparedness and a low level of communication about illness and death, which may also contribute to the increase in caregiver distress.

Hence, caregiver burden seemed to be influenced by factors such as having young children and full-time work. Our findings add to the understanding of the caregivers' situation and indicate that lack of time and concurrent commitments may play a central role for caregiver burden.

In sum, one third of caregivers to terminally ill patients reported psychological distress or caregiver burden. Severe PGS was reported by 15% of all caregivers, 16% suffered from moderate to severe depression, and 11% experienced caregiver burden. Caregiver burden seemed more prevalent in adult children, while partners reported significantly higher levels of pre-loss grief and depression.

## SYMPTOMS OF GRIEF AND DEPRESSION - COMPARISON & PREDICTION (AIM 3)

In our prospective cohort study (*Paper III*), the six months follow-up prevalence of CG was 7.6% and depressive symptoms were 12.1%, and the prevalence of grief and depressive symptoms were higher during caregiving. We show significant predictors regarding personal relation, socio-economic factors, PGS, pre-loss depressive symptoms and preparedness for the death.

### *Symptoms of grief and depression before and after the loss*

The CG prevalence of 8% measured by the PG-13 in this population-based sample was similar to a prevalence of 7% reported in a German population-based study of 1,400 bereaved caregivers (18). However, the German study used the CG measurement tool the ICG-R that has a less restrictive scoring than the PG-13 used in our study. Other studies have reported CG prevalence rates of 6-40% (19-22), which is likely to reflect differences in measurement tools and study population. Hence, prevalence rates should be compared with caution, but the prevalence of 8% in our nationwide, largescale study may establish CG as a complication encountered by a substantial proportion of bereaved caregivers.

Both severe PGS and depressive symptoms were more prevalent in caregivers *before* than *after* the patient's death. Depressive symptoms in caregivers to dementia patients have previously been found to be more prevalent in the period close to the patient's death, whereas only a small proportion of caregivers were depressed six months after the loss (23). Furthermore, 72% felt relief after the death (23).

### *Predictors of adverse bereavement outcome*

#### *Personal relation and socio-economic factors*

Partners were in our study found to have higher levels of CG and PGLD than adult children and other relatives, which is in line with previous studies (24-27). Furthermore, the type and quality of the relationship and whether the relation is identity-defining for the caregiver are important in the caregiver's reaction to bereavement, and the attachment between patient and caregiver may also play a role (21,28).

No association between CG and age or gender was found, while young age and female gender predicted post-loss depressive symptoms. The majority of previous literature found female gender to be associated with higher risk of CG (18,24,27-29), while other studies report higher risk of adverse bereavement outcome in males (28). One reason might be that in our study participants were sampled population-based via postal mail and not sampled through health professionals and at specialized departments. Sampling of participants through health professionals might cause a higher risk of selection of the study population. Hence, both male and female caregivers of all ages may be at risk of developing CG in a palliative care setting, and other factors than age and gender are likely to influence the bereavement process.

### *Symptoms of pre-loss grief and depression*

Severe PGS and pre-loss depressive symptoms strongly predicted CG and post-loss depressive symptoms. Two prior studies conducted in a specialized palliative care setting found that severe PGS was a risk factor for CG (25,26). Almost half of the caregivers from the present cohort who experienced severe PGS also reported pre-loss depressive symptoms. In a factor analysis, PGS were found to be distinct from pre-loss depressive symptoms (30). We analysed whether PGS also predicted bereavement outcome independent of depressive symptoms by applying the multivariable regression model in the subgroup of caregivers without depressive symptoms. We found that severe PGS independently predicted CG and post-loss depressive symptoms. Hence, a condition with severe PGS was a key risk factor of adverse bereavement outcome regardless of caregiver's status of pre-loss depressive symptoms.

Depressive symptoms during the terminal illness trajectory has consistently been associated with adverse bereavement outcome (19,27,31-33). Among caregivers with pre-loss depressive symptoms, 28% developed CG and almost half also reported post-loss depressive symptoms six months post-loss. Our findings underline that PGS and pre-loss depressive symptoms are key predictors for adverse bereavement outcome.

### *Preparedness for death, caregiver burden and communication*

As single variables, preparedness for death, caregiver burden and communication were all predictors of CG and post-loss depressive symptoms. However, in the multivariable analysis the only statistically significant factor was low preparedness that predicted post-loss depressive symptoms. CG was not predicted by low preparedness, high caregiver burden or communication about dying, which contrasts the findings in other studies (24,34,35). In the only earlier prospective preparedness study, low preparedness of the impending death was associated with CG in caregivers to nursing home residents (24). Three retrospective studies also found that low preparedness was associated with CG (19,36,37). An explanation for the discrepancy might be the differences in study populations and design. Thus, in our study severe pre-loss grief symptoms and pre-loss depressive symptoms were the principal predictors which may overweigh e.g. preparedness for death. Still, preparedness for death, caregiver burden and communication may interplay with grief and depressive symptoms in a complex, intertwined pattern, and all factors may play a role in the palliative care trajectory.

In sum, the levels of severe grief symptoms and depressive symptoms were higher during caregiving than at post-loss follow-up. Severe symptoms of pre-loss grief and depressive symptoms were key predictors of CG and post-loss depression. A condition of severe pre-loss grief symptoms was an independent predictor of adverse bereavement outcome also among non-depressed caregivers. Gender and age were not predictors of CG, while being a spouse and having a low educational level were independent predictors of CG and post-loss depression. Still, young age, female gender and low preparedness for the patient's impending death were all predictors of post-loss depression. This risk profile for caregivers to terminally ill patients in a generalized palliative care setting and may be important in the identification of caregivers at risk of CG and post-loss depression.

## SEVERE PRE-LOSS GRIEF SYMPTOMS AND ASSOCIATED FACTORS (AIM 4)

Severe PGS were associated with personal relation, socio-economic factors, depressive symptoms and the palliative caregiving-specific factors caregiver burden, preparedness, communication about dying and prognostic information.

### *Personal relation and socio-economic factors*

Severe PGS was associated with being a partner compared to an adult child or another relations, which has been shown in prior studies (9,25,26). Partners are crucial for caregiver's daily life as they may ensure social companionship, discussions of daily activities, thoughts and emotions as well as avoidance of emotional loneliness (38).

Further, partners are likely to be important for the caregiver's self-definition (39). Hence, the central role partners play in daily life and well-being may explain the higher level of severe grief symptoms found in partners.

Consistent with earlier studies, severe PGS were associated with female gender, young patient age and low education (9,25,30). A low educational level tends to be associated with higher risk of psychological distress (28), although the opposite association has been shown (40). An explanation of the found association could be that low educational level might be related with personal vulnerability and insufficient coping with a demanding situation such as the impending loss of a close relative. Thus, severe PGS might be developed.

### *Depressive symptoms*

Our study show a strong association between severe PGS and depressive symptoms, which have been found in previous small-scale studies of both terminally ill cancer patients and also dementia patients (30,41). Depressive symptoms are commonly associated with predisposing intrapersonal vulnerability, which may rely on an insecure attachment style (42) or they may be a response to the demands of caregiving for a terminally ill relative. These factors linked with insufficient coping efforts may be central for the development of depressive symptoms as well as severe PGS as these two symptoms complexes overlap e.g. regarding the symptoms sadness, guilt and lack of activity (20,43).

### *Preparedness for death and caregiver burden*

Severe PGS were associated with low preparedness for the impending death, which has not been shown in prior studies. Preparedness may entail emotional, cognitive and behavioral dimensions and both practical preparedness regarding e.g. financial affairs and emotional preparedness is important when caregivers are facing the impending death of a close relative (8). The emotional dimension of preparedness has only been sparsely described in the literature. The association between severe grief symptoms and low preparedness could be explained by a lack of emotional preparedness and adaptation to the situation or denial of signs of the impending death. Our findings may indicate that severe PGS in caregivers are connected with lacking preparedness for the death and problems in dealing with the emotional response to multiple losses.

High caregiver burden involves physical and practical demands on the caregiver and also affects emotional and social functioning because of caregiving for a terminally ill relative (17). In this cross-sectional study, no inference can be made on the causation of the relationship between severe PGS and caregiver burden; an explanation of the strong association may be that the emotional elements of caregiver burden are connected with the multiple losses during caregiving that might be expressed as PGS. An earlier study show that perceived high caregiver burden was associated with an emotional coping style in dementia caregivers (17). This could cause one-sided coping mechanisms and inefficient emotional response, which may lead to a constant high level of emotions that might be expressed as severe PGS.

### *Communication*

An association between severe PGS and low communication between the patient and the caregiver about illness and death was found. Low communication has previously been associated with depressive symptoms during caregiving (35). We show a similar association with PGS, which implies that a lack of communication in the family about dying was distressing for a group of caregivers. Yet, caregiver's communication needs are likely to be highly individual and affected by other factors and the family's preferences should be taken into account in clinical care. Caregivers reporting severe PGS were found to be more likely to perceive prognostic information as "too much". However, it is uncertain whether the delivery of prognostic information launched severe PGS in caregivers or the prognostic information was perceived as "too much" due to an emotional state of severe grief symptoms in the caregiver.

In sum, a substantial proportion of caregivers reported severe PGS, which was associated with situational factors (being a spouse, high caregiver burden, low preparedness), predisposing personal vulnerability factors (depression, low education, female gender) and interpersonal factors (low communication, prognostic information). These factors interplay in a complex process and severe PGS may be a key factor in the development of substantial emotional distress in caregivers.

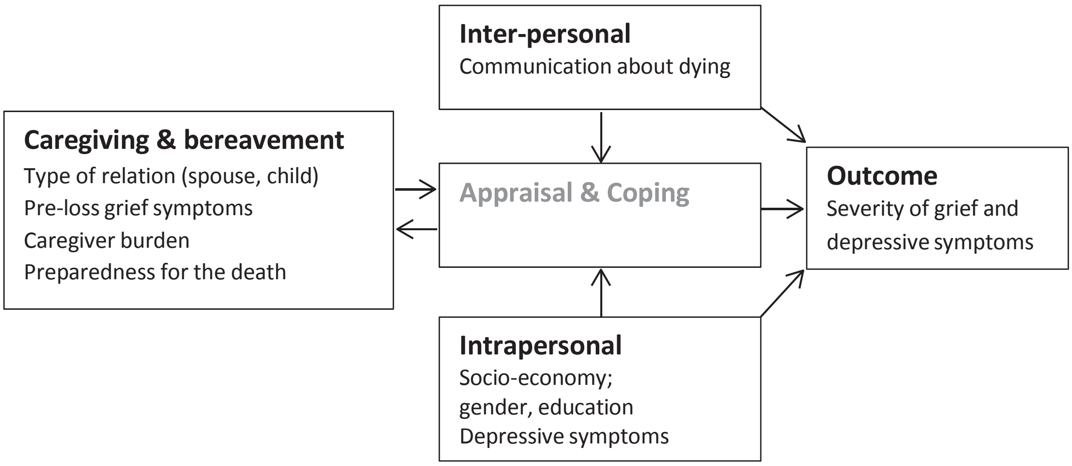
## STUDY FINDINGS IN AN INTEGRATIVE RISK FACTOR MODEL

A range of intrapersonal, interpersonal and situational factors were investigated in the studies of this dissertation An overview of the study findings based on the IRFF is provided in this section. Furthermore, the findings are briefly discussed based on the theories of the IRFF. The first part of this section concerns predictors of CG and depressive symptoms during bereavement (*Paper III*), while the last part addresses severe PGS and associated risk factors in the light of the IRFF (*Paper IV*).

### *A framework for end-of-life caregiving-specific predictors*

The caregiver's process during caregiving and bereavement begins with terminal illness in a close relative. Accordingly, the IRFF (Figure 5.1) may start with the situational factors related to caregiving and bereavement.

*Figure 5.1 The terminal caregiving-specific predictor framework inspired by The Integrative risk factor framework for the prediction of bereavement outcome (5). (Grey text indicates unmeasured factors).*



In the existing literature, PGS was found to be a risk factor for adverse bereavement outcome (*Paper I*). This was supported by in the empirical part of this dissertation; severe PGS was found to be a key predictor of CG and post-loss depressive symptoms. In the IRFF, severe PGS may be seen as a situational factor connected with caregiving for a terminally ill relative, but the factor is not integrated in the original framework by Stroebe et al (28). Other situation factors were low preparedness and high caregiver burden, although only low preparedness continued to be a predictor in multivariable analysis. According to the IRFF the type of relation to the patient (or "type of loss") is a situational factor. Being a partner was found to be a predictor of adverse bereavement outcome, which may underline that the relation to the patient is crucial for caregiver's perceived demands and psychological distress. The investigated interpersonal factor; the level of communication in the family about dying was also was found to be a predictor although not in the multivariable regression analysis. This factor may indicate the family dynamics in connection with terminal illness. The investigated intrapersonal factors were caregiver's pre-loss depressive symptoms, educational level, age and gender. Pre-loss depressive symptoms were found to be a key predictor of adverse bereavement outcome, and low education was persistently associated with both CG and post-loss depressive symptoms. In addition, young age and female gender were found to predict post-loss depressive symptoms but not CG.

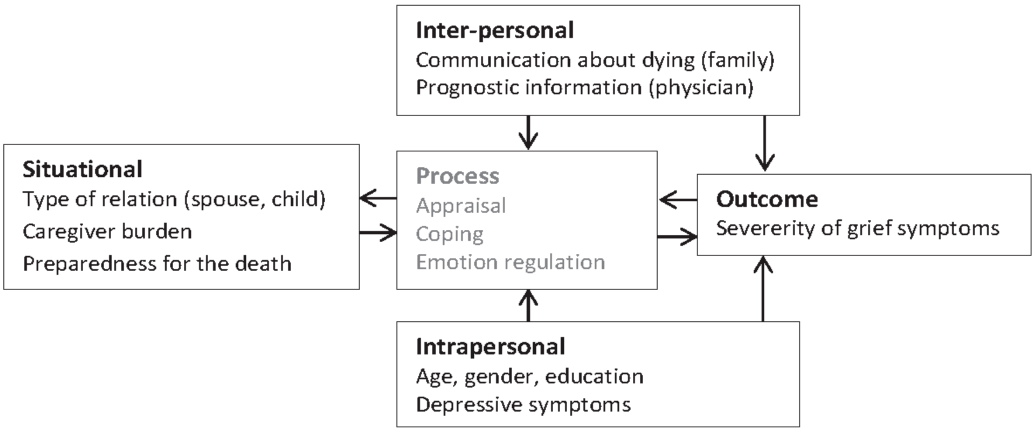
Interpreted in the light of the psychological theories of the IRFF, these predictors interplay in a complex pattern and take part in the caregiver's grief process. Severe PGS, pre-loss depressive symptoms, being a partner and low education were principal factors in this interplay, which may be moderated by unmeasured factors of coping and emotion regulation. In addition, being young and being female were risk factors for the development of post-loss depression. Hence, the IRFF may provide a model for the overview of the several factors influencing the caregiver for the use in assessing caregiver's risk profile and may also stress the influence of processual factors for caregiver's outcome.

### *A risk factor framework for pre-loss grief symptoms during terminal caregiving*

In the light of the psychological theories of the IRFF, caregiver's grief during caregiving may be a complex risk factor for bereavement outcome related to the relationship with the deceased, intrapersonal predisposing factors such as attachment style and interconnected with the caregiver's coping and emotion regulation (Paper I). We set out to empirically investigate severe PGS and associated factors related to terminal caregiving. The investigated factors are outlined in Figure 5.2 on the following page.

Grief during caregiving seems to constitute a complex process, which has been suggested to be 'a reaction to a multiple loss situation' as opposed to 'a reaction to the loss induced by the actual death' (2). Thus, multiple losses may be induced in caregivers to patients with a terminal illness.

*Figure 5.2. Model of investigated factors associated with caregiver's severe grief symptoms based on "The integrative risk factor framework for the prediction of bereavement outcome" by Stroebe et al (2006) (28). (Grey text indicates unmeasured factors).*



Severe grief PGS was found to be associated with the situational factors high caregiver burden and low preparedness. Being a partner to the ill was also an associated factor. Low communication in the family about illness and death and caregivers perception of prognostic information as "too much" were associated interpersonal factors, while pre-loss depressive symptoms, low education and female gender were intrapersonal factors. These factors may interplay with caregiver's severe PGS. In relation to the type of relation, the closeness of the relationship between the patient and the caregiver and caregiver's ability to reorganize bonds between the caregiver and the deceased has been regarded important for psychological adjustment. The ability to make this adaptation of the relationship to the patient is connected with caregiver's attachment style and coping (5). Hence, high levels of grief may be launched in caregiver with inefficient coping. The importance of coping in the grief process and a flexible use of coping strategies may be interpreted as core aspect of the DPM; oscillation between loss- and restoration-oriented stressor is crucial for adaptation to loss (7).

In sum, severe PGS seems to be a key element for caregiver's well-being during the terminal illness trajectory of a close relative. Factors such as caregiver burden was strongly associated with severe PGS and caregiver's coping and emotion regulation are likely to be important in the development of severe PGS.

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# CHAPTER 6:

## MAIN CONCLUSION

Referring to the aims of this dissertation as stated in *Chapter 1*, page 26, this chapter presents the main conclusion drawn from the included papers.

# CONCLUSION OF THE DISSERTATION

Severe suffering was found in a substantial part of caregivers to terminally ill patients. In Paper II, we showed a condition of severe levels of grief symptoms, depressive symptoms and/or caregiver burden in one third of caregivers. In Paper III, we found that levels of grief and depressive symptoms were higher before than after the patient's death. Hence, these findings highlight that caregivers are at high risk of complications during the patient's terminal illness trajectory and may need support.

In Paper III, we showed that severe PGS, pre-loss depressive symptoms, spousal relation and low education were predictors of CG and post-loss depressive symptoms. Interpreted in the light of grief theory and the IRFF, these factors interplay and are mediated by caregiver's coping and emotion regulation. Hence, the findings of this dissertation call for support to caregivers with severe PGS or depressive symptoms during caregiving to alleviate severe psychological distress during bereavement. Assessment of the risk profile for caregivers to terminally ill patients in a generalized palliative care setting may be important in the identification of caregivers at risk of CG and post-loss depression.

In this dissertation, grief symptoms in caregivers before the patient's death was established as a significant factor in end-of-life care; in Paper I, we showed that severe PGS was associated with adverse outcome in earlier studies and in Paper III we showed that severe PGS was a predictor of CG and post-loss depression in the investigated caregiver cohort. We explored associations between severe PGS and determinants of caregiving, which were presented in Paper IV. Our findings showed that severe PGS was connected with several factors indicating caregiver complications during the end-of-life trajectory. Thus, interpreted in the light of the IRFF, severe PGS seem to be a complex phenomenon which is closely related to complications in end-of-life caregiving, personal vulnerability and insufficient coping.

Overall, the findings of this dissertation emphasize that increased attention towards caregivers is required to identify severe symptoms of grief and depression, reduce the risk of adverse bereavement outcomes and improve the end-of-life trajectory for both patients and caregivers. Important new knowledge on severe PGS was also shown; severe grief symptoms before the loss of a close relative may be a key indicator of complications for the caregivers of coping with the difficult position of being a caregiver to a terminally ill patient.

# CHAPTER 7:

## PERSPECTIVES AND FUTURE RESEARCH

The studies of this dissertation filled in several gaps regarding knowledge of grief symptoms in caregivers to terminally ill patients and predictors of adverse bereavement outcome. The findings reveal predictors of psychological distress in bereaved caregivers and point to severe PGS as key indicators of caregiver complications before and after the patient's death. The findings have implications for clinical care and topics suggested for future research will be presented in this Chapter.

## PERSPECTIVES FOR CAREGIVERS IN CLINICAL CARE

Support for caregivers in a patient's end-of-life trajectory is a part of WHO's definition of palliative care (1). The majority of caregivers seems to adapt to the situation of being a caregiver before and after the loss of a close relative and may not need additional support (2). However, support should be directed at caregivers with conditions of high burden and psychological distress during the patient's end-of-life trajectory. These conditions are likely to severely impact caregiver's daily functioning and the entire family during caregiving. This dissertation offers knowledge for use in the identification of caregivers at risk of adverse bereavement outcome and severe PGS. The findings may point to the following suggestions for clinical care:

- Clinical guidelines and continuing education for health professionals in the primary and the secondary sector may improve the knowledge regarding caregivers' situation and risk of burden and psychological distress, which form the basis for provision of targeted support and identification of caregivers with special support needs.
- It is essential to monitor caregivers' needs, burden and psychological distress in order to provide targeted support. Furthermore, regular assessment of caregivers' risk profile for adverse bereavement outcome is suggested. This calls for ongoing contact between the family and the involved health professionals.
- Targeted interventions may be facilitated by the health professional using a person-centered approach (3). They may be directed at reduction of caregiver burden, improvement of preparedness, treatment of depressive symptoms and support for caregivers with severe PGS.
- Knowledge on specific interventions for caregivers with severe PGS is needed (4). In studies of CG, psychotherapy directed at both loss-oriented and restoration-oriented stressors and the oscillation between these stressors (the core elements of the DPM (5)) have been shown to facilitate adaptation to the loss in bereaved caregivers (6,7). A similar treatment strategy is suggested in the support of caregivers with severe PGS; treatment directed at shifting between the difficult *losses* during the patient's illness trajectory and *restoration*, e.g. future plans, may support caregivers in the situation of facing bereavement.

## FUTURE RESEARCH

Based on this dissertation, two important areas may be crucial to investigate in future studies; assessment and interventions.

Assessments:

- Development of a risk assessment tool may facilitate the identification of caregivers with a high risk profile for adverse bereavement outcome. On the basis of existing research, such a tool should be developed and tested for feasibility and effect in generalized and specialized palliative care settings.
- A standardized assessment tool is needed to identify severe PGS in clinical care and in research. Thus, psychometric testing of measurement tools such as the pre-loss version of PG-13 is suggested.

Interventions:

- Interventions for caregivers with high levels of burden and distress are necessary. Targeted interventions may support different aspects that are relevant for the individual caregiver engaged in end-of-life palliative care. Nevertheless, our findings highlight that PGS may be a crucial warning sign of complications during caregiving which may indicate problems with caregivers’ coping with a difficult situation. Therefore, future studies are needed of interventions directed at caregiver’s coping and emotion regulation on severe PGS.
- Interventions may take different approaches and does not necessarily need to be resource-demanding for health professionals. A phone-call to the caregiver might improve the possibility to focus on caregiver’s needs instead of the patient’s needs (8). Modern IT technologies may also provide new opportunities for supporting caregivers. For instance, internet-based programs or smart phone applications for caregivers might provide individual support and information on when and where to seek face-to-face support, if needed. Such interventions studies are warranted in future studies.

References of Chapter 7

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# ENGLISH SUMMARY

### *Background*

Facing bereavement and the loss of a close relative with a terminal illness places the caregiver in a vulnerable position. As terminal illnesses affects a considerable proportion of the population, the number of caregivers to terminally ill patients is significant. Participation in provision of care for a severely ill relative is important for many caregivers; it helps the patient, benefits the caregiver and relieves the healthcare system. Still, there is a considerable risk that the demands and the distress of caregiving may exceed the caregiver's resources, which may result in high levels of grief symptoms, depressive symptoms and caregiver burden. These conditions may impair daily life functioning and might have major consequences for the caregiver during caregiving and the journey into bereavement. Adverse bereavement outcomes include complicated grief (defined as persistent severe grief symptoms and impairment of functioning) and depressive symptoms. Knowledge on factors indicating complications in the caregiver during caregiving and bereavement is crucial to adequately support caregivers. However, only few population-based studies have investigated these factors. Especially the role of grief during caregiving seems to be sparsely investigated. These topics are the focus of the present dissertation.

In caregivers to terminally ill patient, we aimed to investigate:

- pre-loss grief symptoms and preparedness in earlier studies,
- the prevalence of severe pre-loss grief symptoms, depressive symptoms and high caregiver burden in a population-based caregiver cohort,
- severe grief and depressive symptoms before and after the death and palliative caregiving-specific and socioeconomic predictors of adverse bereavement outcome and
- associations of severe pre-loss grief with palliative caregiving-specific and socioeconomic factors.

### *Methods*

To meet the first aim, we conducted a systematic review according to the PRISMA guidelines. To address the three other aims, we conducted a nationwide prospective population-based study of a systematically recruited cohort of caregivers to patients granted drug reimbursement in 2012. Of the 9,512 eligible patients, who were sent an invitation letter and an enclosed questionnaire for their closest caregiver, 3,635 caregivers (38%) completed the questionnaire. The patients' survival was monitored, and caregivers who were bereaved within six months (n=2,420) were mailed a follow-up questionnaire six months after the loss. Of these, 2,215 (88%) participated. The conducted analyses were based on data from questionnaires at baseline and at follow-up in combination with register-based data on socioeconomic factors.

### *Results*

Severe PGS were the review of earlier studies found to be a risk factor of adverse bereavement outcome (Paper I). In the light of contemporary grief theory and the IRFF, grief during caregiving may be interpreted as complex risk factors for adverse bereavement outcome that interplay with various other factors including caregiver's coping and emotion regulation.

In total, one third of caregivers to terminally ill patients reported severe pre-loss grief symptoms (15%), moderate to severe depressive symptoms (16%) and/or high caregiver burden (11%). Partners reported higher levels of pre-loss grief and depression than adult children, whereas high caregiver burden seemed more prevalent in adult children (Paper II). The levels of severe grief symptoms and moderate to severe depressive symptoms were higher during caregiving compared to six months after the loss (Paper III). Pre-loss symptoms of grief and depression were predictors of CG and post-loss depression. Furthermore, severe pre-loss grief symptoms were an independent predictor of adverse bereavement outcome, also among non-depressed caregivers. Being a partner and having a low educational level were independent predictors of CG and post-loss depression, while young age, female gender and low preparedness for the patient's impending death were all predictors of post-loss depression only (Paper III).

In Paper IV, we found that severe PGS were associated with being a partner, female gender, low education, symptoms of depression, high caregiver burden, low preparedness and low communication.

### *Conclusion and perspectives*

A substantial number of caregivers to terminally ill patients were found to have adverse reactions during caregiving. The levels of severe grief and depressive symptoms were higher before than after the loss, which might underline the need for support for a specific group of caregivers during caregiving. Development of complicated grief and post-loss depression was strongly predicted by severe symptoms of grief and depression, which emphasizes the need for attention towards these conditions. Furthermore, socio-economic factors such as being a partner and having a low educational level were predictors of adverse bereavement outcome; this calls for assessment of caregiver's risk profile during caregiving in order to identify and support caregivers at high risk.

Severe PGS seems to be linked with adverse bereavement outcome both in earlier studies associated and in the questionnaire study of this dissertation. Severe PGS may thus be a key indicator of complications in the caregiver about coping with patient's terminal illness.

This new knowledge calls for increased attention towards caregivers' well-being during the patient's terminal illness trajectory. Interventions from health professionals may be crucial to support caregivers in their coping with symptoms of severe grief, to treat depressive symptoms and to provide individualized support for caregivers during caregiving and bereavement.

# DANSK RESUME

### *Baggrund*

For mange pårørende til en terminalt syg patient er den sidste tid en svær periode. Da terminal sygdom er en realitet for mange mennesker, er det et betydeligt antal pårørende, der oplever at skulle gennem denne svære tid. For mange pårørende er det afgørende at deltage i omsorgen for den syge i den sidste tid, og det støtter patienten, hjælper den pårørende og aflaster sundhedsvæsenet. Der er dog en betydelig risiko for at belastningen ved at være pårørende overskrider den pårørendes ressourcer. Det kan medføre et højt niveau af belastning (*caregiver burden*), svære symptomer på sorg før død og depression og kan hæmme den pårørendes daglige funktion, hvilket kan have vidtrækkende konsekvenser for familien under sygdomsperioden og i tiden efter dødsfaldet. Efter dødsfaldet kan den efterlevende risikere at udvikle kompliceret sorg, hvilket defineres som vedblivende svære sorgsymptomer, der hæmmer den daglige funktion, og depression.

Det er afgørende at få mere viden om, hvilke faktorer der er forbundet med udvikling af komplikationer hos den pårørende under et sygdomsforløb og efter dødsfaldet, hvis pårørende skal kunne få den nødvendige støtte. Imidlertid mangler der større undersøgelser, der kan belyse disse faktorer. Særligt betydningen af sorgsymptomer hos den pårørende inden patientens dødsfald synes at være sparsomt undersøgt. Derfor fokuserer denne afhandling på disse problemstillinger.

Formålet med afhandlingen var blandt pårørende til alvorligt syge at undersøge:

- Pårørendes sorgsymptomer inden patientens død og graden af forberedthed på dødsfaldet på baggrund af tidligere studier
- Forekomsten af sorgsymptomer inden patientens død, depressionssymptomer og *caregiver burden* i en større undersøgelse af pårørende i den danske befolkning
- Hvorvidt faktorer vedrørende forløbet op til patientens død og socioøkonomiske faktorer kan prædiktere udviklingen af kompliceret sorg og depression efter patientens død
- Sammenhængen mellem svære sorgsymptomer før patientens død og henholdsvis faktorer vedrørende forløbet op til patientens død og socioøkonomiske faktorer.

### *Metoder*

For at undersøge det første formål lavede vi en systematisk oversigtsartikel (*review*) af tidligere studier i henhold til PRISMA-guidelines. De resterende formål er blevet undersøgt på baggrund af analyser, som bygger på en gennemført dansk prospektiv populationsundersøgelse af pårørende. Disse blev (systematisk) inviteret til at deltage i undersøgelsen via invitationsbreve til patienter, som fik bevilget terminaltilskud i 2012. I alt 9.512 patienter fik tilsendt et brev med et spørgeskema til deres nærmeste pårørende, og i alt 3.635 pårørende (38 %) valgte at udfylde og returnere spørgeskemaet. Patienternes overlevelse blev fulgt, og pårørende til patienter, der døde inden for et halvt år (n=2.420), fik tilsendt et opfølgende spørgeskema seks måneder efter patientens død. Heraf valgte 2.215 pårørende (88 %) at besvare og returnere spørgeskemaet. Undersøgelsens analyser er baseret på data fra spørgeskemaer ved baseline og ved opfølgning samt data fra nationale danske registre om socioøkonomiske faktorer.

### *Resultater*

Tidligere studier viste, at svære sorgsymptomer og lav forberedthed på patientens død var risikofaktorer for komplikationer efter dødsfaldet (Artikel I). Set i lyset af førende sorgteorier kan sorg før patients død fortolkes som en kompleks risikofaktor for komplikationer efter dødsfaldet, der spiller sammen med adskillige andre faktorer, bl.a. den pårørendes *coping* og følelsesregulering.

En ud af tre pårørende til alvorligt syge angav enten svære sorgsymptomer før død (15 %), moderate til svære depressive symptomer (16 %) og/eller *caregiver burden* (11 %). Partnere rapporterede generelt højere niveauer af svære symptomer på sorg før død og depression, mens høj *caregiver burden* syntes at være mere hyppigt forekommende blandt voksne børn (Artikel II). Niveauet af svære symptomer på sorg før død og depression var højere før patientens død sammenlignet med seks måneder efter patientens død (Artikel III). Symptomer på sorg og depression før patientens død prædikterede kompliceret sorg og depressive symptomer efter patientens død. Desuden var svære sorgsymptomer før død en prædiktor for kompliceret sorg og depressive symptomer efter død blandt pårørende uden depressive symptomer før dødsfaldet. At være partner til patienten og at have et lavt uddannelsesniveau var uafhængige prædiktorer for kompliceret sorg og depressive symptomer efter dødsfaldet, mens ung alder, kvindeligt køn og lav forberedthed på patientens død kun var prædiktorer for depressive symptomer efter død (Artikel III).

Artikel IV viste, at svære sorgsymptomer inden død var associeret med en række faktorer bl.a. at være partner til den syge, kvindeligt køn, lavt uddannelsesniveau, depressive symptomer, høj *caregiver burden*, lav forberedthed og lavt niveau af kommunikation i familien om den forestående død.

### *Konklusioner og perspektiver*

Et betydeligt antal pårørende til alvorligt syge havde reaktioner, som var forbundet med komplikationer under patientens sygdomsforløb og efter dødsfaldet. Kompliceret sorg og depressive symptomer efter dødsfaldet var i høj grad prædikterede af svære symptomer på sorg og depression før død, hvilket understreger, at der er behov for øget opmærksomhed på disse tilstande i pårørende til alvorligt syge patienter. Desuden prædikterede visse socio-økonomiske faktorer kompliceret sorg og depression efter dødsfaldet. Fundene peger på, at de pårørendes risikoprofil bør evalueres under patientens sygdom for at sikre, at der ydes støtte til pårørende i høj risiko.

Svære sorgsymptomer før død var både i tidligere studier og i spørgeskemaundersøgelsen i denne afhandling associeret med komplikationer efter dødsfaldet. Pårørendeundersøgelse forbinder desuden fænomenet svær sorg før dødsfald med komplikationer hos den pårørende allerede inden patientens død, og svære sorgsymptomer før død synes at være en nøgleindikator for pårørendes komplikationer under patientens sygdomsforløb.

Denne nye viden peger på, at der behov for øget opmærksomhed på pårørendes tilstand under terminale sygdomsforløb. Der er behov for en systematisk evaluering af pårørendes behov og psykiske tilstand, så de pårørende, som er i risiko for at udvikle komplikationer før og efter en patients død, kan blive identificeret og få hjælp. Det er således vigtigt at give individualiseret støtte til pårørende både under før og efter patientens død herunder aflastning af den pårørende under sygdomsforløbet, behandling af en eventuel depression og ikke mindst hjælp til pårørende i deres håndtering af svære sorg symptomer.

# APPENDICES A-D

# Appendix A: Invitation letter for patients and caregivers at baseline

Aarhus Universitetshospital

FORSKNINGSENHEDEN
FOR ALMEN PRAKSIS
Århus

Dato/lbnr

**Navn (patient)**
**og adresse**

## Indbydelse til <u>din pårørende</u> om at deltage i en spørgeskemaundersøgelse

**Kære ”navn”**

Vi sender dette brev til dig, fordi vi fra sundhedsvæsenets registre har fået oplyst, at du har fået bevilget gratis medicin pga. alvorlig sygdom. Gennem denne spørgeskemaundersøgelse vil vi gerne sætte fokus på, hvordan pårørende til alvorligt syge har det. Vi har stor forståelse for, at det er en svær tid for dig og din familie. Vi håber ikke, at det virker stødende, at vi kontakter dig. Vores håb er, at din pårørende vil deltage i undersøgelsen og dermed bidrage til, at patienter og deres pårørende kan tilbydes den bedst mulige støtte fra sundhedsvæsenet.

### Hvad beder vi dig om?

Vi vil bede dig videregive vedlagte spørgeskema og det medfølgende brev til din <u>ægtefælle</u> eller <u>samlever.</u> Hvis du ikke er gift eller samlevende, beder vi dig give det til en anden <u>nær pårørende</u>. Er der sket en fejlregistrering, eller har du en anden årsag til ikke at kunne hjælpe, undskylder vi meget vores henvendelse og beder dig venligst angive årsagen herunder og returnere dette brev i den frankerede svarkuvert:

☐ **Jeg får <u>ikke</u> gratis medicin pga. alvorlig sygdom – der må være sket en fejl**
☐ **Jeg ønsker ikke at videregive spørgeskemaet til én af mine pårørende**
☐ **Jeg mener ikke, at jeg har en nær pårørende at videregive spørgeskemaet til**
☐ **Andet: __________________________________________________**

Hvis du har spørgsmål eller kommentarer, er du meget velkommen til at kontakte den projektansvarlige læge Mette Kjærgaard Nielsen på tlf. 87 16 83 69 eller e-mail: mette.nielsen@alm.au.dk. Alle informationer behandles strengt fortroligt! Hvis vi ikke har modtaget spørgeskemaet fra din pårørende eller dette brev fra dig inden for 2-3 uger, tillader vi os at sende en påmindelse.

## Mange tak for din hjælp!

**Venlig hilsen**

Mette Kjærgaard Nielsen

Mette Kjærgaard Nielsen
Projektansvarlig, læge
Forskningsenheden for Almen Praksis, Aarhus

Mette Asbjørn Neergaard
Afdelingslæge, ph.d.
Det Palliative Team, Aarhus Universitetshospital

Flemming Bro
Forskningsleder, professor, dr.med.
Forskningsenheden for Almen Praksis, Aarhus

Anders Bonde Jensen
Overlæge, ph.d.
Onkologisk Afdeling, Aarhus Universitetshospital

Aarhus Universitetshospital

FORSKNINGSENHEDEN
FOR ALMEN PRAKSIS
Århus

Dato/lbnr

## Kære pårørende til ”navn”

## Indbydelse til at deltage i en spørgeskemaundersøgelse

Vi har bedt ”navn” videregive dette spørgeskema til dig som nær pårørende. Gennem denne spørgeskemaundersøgelse vil vi gerne sætte fokus på, hvordan pårørende til alvorligt syge har det. Vi ønsker at se på pårørendes forskellige behov for hjælp, således at den enkelte kan gives optimal støtte fra sundhedspersonale til gavn for både patienter og pårørende.
Vi har stor forståelse for, at det er en svær tid for dig og din familie, og vi håber ikke, at det virker stødende, at vi har kontaktet jer. Vores håb er, at du vil deltage i undersøgelsen og dermed bidrage til, at vi i sundhedsvæsenet kan blive bedre til at hjælpe patienter og pårørende, der går igennem en meget svær tid.

### Hvad beder vi dig om?

Vi har vedlagt et spørgeskema, som vi håber, du vil tage dig tid til at udfylde og sende tilbage til os i den vedlagte frankerede svarkuvert. Det tager ca. 30 min. at udfylde spørgeskemaet. Hvis du har behov for hjælp til det, er det helt i orden at få hjælp af en nærtstående.
Har du har spørgsmål eller kommentarer til os, er du velkommen til at ringe eller skrive til projektansvarlige læge, Mette Kjærgaard Nielsen, på telefonnummer: 87 16 83 69 eller e-mail: mette.nielsen@alm.au.dk.
Skulle du ikke ønske at udfylde selve spørgeskemaet, beder vi dig venligst om alligevel at udfylde skemaets første side og returnere den, og så vil vi selvfølgelig ikke ulejlige dig mere.

### Fortrolighed

Alle informationer behandles strengt fortroligt. Kun forskergruppen får adgang til besvarelsen, så ingen af jeres behandlere i sundhedsvæsenet får kendskab til din deltagelse og dine besvarelser. Undersøgelsen er godkendt af Datatilsynet og er forelagt Den Videnskabsetiske Komité.

For at forbedre sundhedsvæsenets indsats fremover er det vigtigt, at så mange som muligt deltager i undersøgelsen. Vi håber derfor at modtage dit udfyldte spørgeskema som bidrag til undersøgelsen.

## Mange tak for din hjælp!

**Venlig hilsen**

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# Appendix B: Questionnaire for caregivers at baseline

# At være pårørende...

## En spørgeskemaundersøgelse af pårørende til alvorligt syge

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Aarhus Universitet

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Forskningsenheden for Almen Praksis

Aarhus Universitetshospital

At være pårørende...

Forskningsenheden for Almen Praksis
Aarhus Universitet
Bartholins Allé 2
8000 Aarhus C

## Generelle oplysninger

De indledende spørgsmål handler om dig og om din pårørendes sygdom. Du bedes oplyse dit cpr-nummer, så vi har mulighed for at sende dig et nyt spørgeskema på et senere tidspunkt.

**Dit fulde navn** ____________________

**Dit cpr-nummer** ☐☐☐☐☐☐ - ☐☐☐☐

**1.1** **Dato for udfyldelse af skemaet** ☐☐ - ☐☐ - 2 0 ☐☐

**1.2** **Hvilken relation har du til din pårørende? Han/hun er min:** (Sæt kun ét kryds)

- ☐ Ægtefælle
- ☐ Samlever
- ☐ Kæreste, men vi bor ikke sammen
- ☐ Mor/far
- ☐ Datter/søn
- ☐ Søster/bror
- ☐ Svigerdatter/svigersøn
- ☐ Veninde/ven
- ☐ Anden. Angiv venligst hvilken:____________________

Forbeholdt kodning ☐☐

**1.3** **Pga. hvilken sygdom har din pårørende fået bevilget gratis medicin?** (Sæt kun ét kryds)

- ☐ Kræft
- ☐ Lungesygdom (f.eks. rygerlunger/KOL)
- ☐ Hjertesygdom (f.eks. hjertesvigt)
- ☐ Neurologisk sygdom (f.eks. sklerose)
- ☐ Nyresygdom (f.eks nyresvigt)
- ☐ Anden sygdom. Angiv venligst hvilken:____________________

Forbeholdt kodning ☐☐

**1.4** **Hvornår fik din pårørende konstateret sygdommen?** (Skriv måned og år)

☐☐ - ☐☐☐☐
måned år

**1.5** **Har du officiel plejeorlov?**

- ☐ Ikke relevant, da jeg ikke er på arbejdsmarkedet
- ☐ Nej, jeg har ikke orlov
- ☐ Ja, jeg har plejeorlov med økonomisk kompensation: Fuldtid? ☐ Deltid? ☐
- ☐ Anden orlov, f.eks. taget fri eller er sygemeldt: Fuldtid? ☐ Deltid? ☐

## Støtte fra familie og venner

De følgende spørgsmål handler om dit forhold til andre mennesker.

**2.1** **Hvor ofte er du i kontakt med venner, bekendte og familie, som du ikke bor sammen med?** Med kontakt menes der, at I er sammen, taler i telefon sammen, skriver til hinanden m.v. (Sæt kun ét kryds)

| Dagligt eller næsten dagligt ▼ | 1 eller 2 gange om ugen ▼ | 1 eller 2 gange om måneden ▼ | Sjældnere end 1 gang om måneden ▼ | Aldrig ▼ |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |

**2.2** **Hvordan vil du vurdere den støtte, du får fra dine nærmeste venner og familie?** (Sæt kun ét kryds)

- ☐ Fremragende
- ☐ God
- ☐ Mindre god
- ☐ Dårlig

**2.3** **Sker det nogensinde, at du er alene, selvom du mest har lyst til at være sammen med andre?** (Sæt kun ét kryds)

- ☐ Ja, ofte
- ☐ Ja, engang imellem
- ☐ Ja, men sjældent
- ☐ Nej
- ☐ Ved ikke

**2.4** **Har du nogen at tale med, hvis du har problemer eller brug for støtte?** (Sæt kun ét kryds)

- ☐ Ja, ofte
- ☐ Ja, for det meste
- ☐ Ja nogen gange
- ☐ Nej, aldrig eller næsten aldrig
- ☐ Ved ikke

## Kontakt med sundhedspersonale

Nu vil vi bede dig besvare nogle spørgsmål om jeres eventuelle kontakt med hjemmeplejen, praktiserende læge og palliativt team. Med et "palliativt team" mener vi et team af læger, sygeplejersker, psykologer, socialrådgivere m.fl., som udelukkende tager sig af alvorligt syge patienter og deres pårørende.

**3.1 I hvor høj grad vurderer du, at nedenstående sundhedspersonale yder den indsats, som <u>din pårørende</u> har brug for?**

| (Sæt kun ét kryds i hver linje) | I høj grad ▼ | I nogen grad ▼ | I mindre grad ▼ | Slet ikke ▼ | Ingen kontakt ▼ |
|---|---|---|---|---|---|
| A Hjemmesygeplejerskerne | ☐ | ☐ | ☐ | ☐ | ☐ |
| B Hjemmehjælperne | ☐ | ☐ | ☐ | ☐ | ☐ |
| C Din pårørendes praktiserende læge | ☐ | ☐ | ☐ | ☐ | ☐ |
| D Palliativt team | ☐ | ☐ | ☐ | ☐ | ☐ |

**3.2 I hvor høj grad vurderer du, at nedenstående sundhedspersonale yder den indsats, som <u>du</u> har brug for?**

| (Sæt kun ét kryds i hver linje) | I høj grad ▼ | I nogen grad ▼ | I mindre grad ▼ | Slet ikke ▼ | Ingen kontakt ▼ |
|---|---|---|---|---|---|
| A Hjemmesygeplejerskerne | ☐ | ☐ | ☐ | ☐ | ☐ |
| B Hjemmehjælperne | ☐ | ☐ | ☐ | ☐ | ☐ |
| C Din praktiserende læge | ☐ | ☐ | ☐ | ☐ | ☐ |
| D Palliativt team | ☐ | ☐ | ☐ | ☐ | ☐ |

**3.3 Hvor ofte kommer der hjemmesygeplejersker og hjemmehjælpere hjemme hos din pårørende?**

| (Sæt kun ét kryds i hver linje) | Hver dag ▼ | Hver uge ▼ | Hver måned ▼ | Aldrig ▼ |
|---|---|---|---|---|
| A Hjemmesygeplejersker | ☐ | ☐ | ☐ | ☐ |
| B Hjemmehjælpere | ☐ | ☐ | ☐ | ☐ |

## Omsorgsgiver

De næste spørgsmål handler om din situation som omsorgsgiver for din pårørende. Med ordene "omsorgsgiver" og "at give omsorg" mener vi at tage sig af sin pårørende med alt, hvad det indebærer. Det er vigtigt, at du besvarer alle spørgsmål, selv om du muligvis synes, at nogle af dem ikke passer på din situation.

**4.1 Hvor meget tid bruger du pr. døgn på …**

| (Sæt kun ét kryds i hver linje) | 0-2 timer ▼ | 3-8 timer ▼ | 9-16 timer ▼ | 17-24 timer ▼ |
|---|---|---|---|---|
| A. … at være omsorgsgiver for din pårørende? | ☐ | ☐ | ☐ | ☐ |
| B. … pleje og praktisk hjælp til din pårørende, f.eks. bad, mad, toiletbesøg, medicinhåndtering? | ☐ | ☐ | ☐ | ☐ |

**Læs venligst hvert af de følgende udsagn, og vælg det svar, som bedst beskriver din situation.**

| (Sæt kun ét kryds i hver linje) | Ja, i høj grad ▼ | Ja, i nogen grad ▼ | Nej, i mindre grad ▼ | Nej, slet ikke ▼ |
|---|---|---|---|---|
| **4.2** Jeg føler mig frisk og udhvilet, når jeg står op om morgenen | ☐ | ☐ | ☐ | ☐ |
| **4.3** Den omsorg, jeg giver, har gjort mig mindre tilfreds med mit liv | ☐ | ☐ | ☐ | ☐ |
| **4.4** Jeg føler mig ofte fysisk udmattet | ☐ | ☐ | ☐ | ☐ |
| **4.5** Fra tid til anden ønsker jeg, at jeg kunne "flygte" fra den situation, jeg er i | ☐ | ☐ | ☐ | ☐ |
| **4.6** Jeg ville ønske, jeg kunne tale med andre om min rolle som omsorgsgiver | ☐ | ☐ | ☐ | ☐ |
| **4.7** Jeg har tid nok til mine egne behov og interesser | ☐ | ☐ | ☐ | ☐ |
| **4.8** Jeg føler mig værdsat af den person, jeg giver omsorg | ☐ | ☐ | ☐ | ☐ |
| **4.9** Jeg kan koble fra, når jeg ikke "har vagten" | ☐ | ☐ | ☐ | ☐ |
| **4.10** Jeg har det godt med at stå for den nødvendige pleje (personlig hygiejne, give mad osv.) | ☐ | ☐ | ☐ | ☐ |
| **4.11** Nogle gange føler jeg ikke rigtigt, at jeg er mig selv længere | ☐ | ☐ | ☐ | ☐ |

| (Sæt kun ét kryds i hver linje) | Ja, i høj grad ▼ | Ja, i nogen grad ▼ | Nej, i mindre grad ▼ | Nej, slet ikke ▼ |
|---|---|---|---|---|
| **4.12** Den omsorg og pleje, jeg giver, er fuldt anerkendt af andre (f.eks. familie og venner) | ☐ | ☐ | ☐ | ☐ |
| **4.13** Min rolle som omsorgsgiver har påvirket min økonomiske situation | ☐ | ☐ | ☐ | ☐ |
| **4.14** Jeg følte mig presset ind i rollen som omsorgsgiver | ☐ | ☐ | ☐ | ☐ |
| **4.15** Kravene fra den person, jeg passer, er efter min mening rimelige | ☐ | ☐ | ☐ | ☐ |
| **4.16** Jeg føler, at jeg har styr på pasningen af min pårørende | ☐ | ☐ | ☐ | ☐ |
| **4.17** Pasningen af min pårørende påvirker mit helbred | ☐ | ☐ | ☐ | ☐ |
| **4.18** Jeg er stadig i stand til at føle mig rigtig glad | ☐ | ☐ | ☐ | ☐ |
| **4.19** Jeg har måttet opgive fremtidsplaner på grund af min rolle som omsorgsgiver | ☐ | ☐ | ☐ | ☐ |
| **4.20** Jeg har det fint med, når udenforstående oplever den situation, min pårørende er i | ☐ | ☐ | ☐ | ☐ |
| **4.21** Jeg føler mig følelsesmæssigt drænet af rollen som omsorgsgiver | ☐ | ☐ | ☐ | ☐ |
| **4.22** Jeg føler mig splittet mellem kravene fra mine omgivelser (f.eks. min familie) og det at give pleje og omsorg | ☐ | ☐ | ☐ | ☐ |
| **4.23** Jeg synes, jeg har et godt forhold til den person, jeg tager mig af | ☐ | ☐ | ☐ | ☐ |
| **4.24** Jeg har problemer med nogle af mine familiemedlemmer pga. "rollen" som den, der giver omsorg | ☐ | ☐ | ☐ | ☐ |
| **4.25** Jeg føler, at jeg har brug for en pause | ☐ | ☐ | ☐ | ☐ |
| **4.26** Jeg er bekymret for, hvordan det, at jeg tager mig af min pårørende, vil påvirke min fremtid | ☐ | ☐ | ☐ | ☐ |
| **4.27** Mit forhold til familien, mine venner og bekendte lider pga. min rolle som den, der giver omsorg | ☐ | ☐ | ☐ | ☐ |
| **4.28** Min pårørendes skæbne gør mig bedrøvet | ☐ | ☐ | ☐ | ☐ |
| **4.29** Jeg kan udmærket passe andre daglige pligter ved siden af min rolle som den, der giver omsorg | ☐ | ☐ | ☐ | ☐ |

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## Reaktion på alvorlig sygdom

Nedenstående handler om din reaktion på din pårørendes alvorlige sygdom. Det er vigtigt, at du besvarer alle spørgsmål, selv om du muligvis synes, at nogle af dem ikke passer på din situation.

**Hvor ofte har du inden for den sidste måned ...**

| (Sæt kun ét kryds i hver linje) | Slet ikke ▼ | Mindst én gang ▼ | Mindst en gang om ugen ▼ | Mindst en gang om dagen ▼ | Flere gange dagligt ▼ |
|---|---|---|---|---|---|
| **5.1** … følt længsel og savn efter tiden før din pårørendes sygdom? | ☐ | ☐ | ☐ | ☐ | ☐ |
| **5.2** … oplevet intens følelsesmæssig smerte, bedrøvelse eller stik af sorg relateret til din pårørendes sygdom? | ☐ | ☐ | ☐ | ☐ | ☐ |
| **5.3** … forsøgt at undgå påmindelser om, at din pårørende er alvorligt syg? | ☐ | ☐ | ☐ | ☐ | ☐ |
| **5.4** … følt dig lamslået, chokeret eller forvirret pga. sygdommen? | ☐ | ☐ | ☐ | ☐ | ☐ |

**Angiv venligst ved hvert spørgsmål, hvordan du har det for tiden.**

| (Sæt kun ét kryds i hver linje) | Slet ikke ▼ | Lidt ▼ | Noget ▼ | En hel del ▼ | Virkelig meget ▼ |
|---|---|---|---|---|---|
| **5.5** Føler du dig forvirret i forhold til din rolle i livet, eller har du det som om, du ikke ved, hvem du selv er (dvs. som om en del af dig er død)? | ☐ | ☐ | ☐ | ☐ | ☐ |
| **5.6** Har du haft svært ved at acceptere, at din pårørende er syg? | ☐ | ☐ | ☐ | ☐ | ☐ |
| **5.7** Har det været svært for dig at stole på andre mennesker, efter at din pårørende fik konstateret sygdommen? | ☐ | ☐ | ☐ | ☐ | ☐ |
| **5.8** Føler du dig bitter over din pårørendes sygdom? | ☐ | ☐ | ☐ | ☐ | ☐ |

| (Sæt kun ét kryds i hver linje) | Slet ikke ▼ | Lidt ▼ | Noget ▼ | En hel del ▼ | Virkelig meget ▼ |
|---|---|---|---|---|---|
| **5.9** Har du svært ved at koncentrere dig eller gøre de ting, du plejer, fordi du tænker på din pårørendes sygdom? | ☐ | ☐ | ☐ | ☐ | ☐ |
| **5.10** Har du en følelse af tomhed, efter at sygdommen er blevet konstateret? | ☐ | ☐ | ☐ | ☐ | ☐ |
| **5.11** Føler du, at livet er utilfredsstillende, tomt eller meningsløst, fordi din pårørende ikke er rask? | ☐ | ☐ | ☐ | ☐ | ☐ |

**5.12** **Har du oplevet en betydelig begrænsning på sociale, arbejdsrelaterede eller andre funktionsområder (f.eks. huslige pligter)?** (Sæt kun ét kryds)

☐ Ja ☐ Nej

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## Følelsesmæssig reaktion

Nedenstående udsagn handler om din følelsesmæssige reaktion på din situation. Vi ser på din samlede besvarelse af udsagnene. Derfor er det vigtigt, at du tager stilling til alle grupper af udsagn, selv om du muligvis synes, at nogle af dem ikke passer på din situation.

**Læs venligst hver gruppe af udsagn grundigt og vælg det udsagn i hver gruppe, der bedst beskriver, hvordan du har følt det de seneste 2 uger.**
(Sæt kun ét kryds i hvert spørgsmål)

**6.1 Tristhed**

☐ 0 Jeg føler mig ikke trist

☐ 1 Jeg er ofte trist

☐ 2 Jeg er trist hele tiden

☐ 3 Jeg er så trist og ked af det, at jeg ikke kan holde det ud

**6.2 Pessimisme**

☐ 0 Jeg er ikke bekymret for min fremtid

☐ 1 Jeg er mere bekymret for min fremtid, end jeg plejer

☐ 2 Jeg forventer, at min fremtid vil udvikle sig i negativ retning

☐ 3 Jeg føler, at fremtiden er håbløs, og at det kun kan blive værre

**6.3 Tidligere nederlag**

☐ 0 Jeg føler mig ikke mislykket

☐ 1 Jeg har klaret mig dårligere, end jeg burde

☐ 2 Jeg har mange nederlag bag mig

☐ 3 Jeg føler mig som en total fiasko

**6.4 Manglende glæde**

☐ 0 Jeg oplever lige så stor glæde ved tilværelsen, som jeg plejer

☐ 1 Jeg glæder mig ikke så meget over tilværelsen, som jeg plejer

☐ 2 Jeg har meget lidt fornøjelse af de ting, jeg tidligere kunne glæde mig over

☐ 3 Jeg har slet ingen fornøjelse af det, jeg tidligere kunne glæde mig over

**6.5 Skyldfølelse**

☐ 0 Jeg plages ikke specielt af dårlig samvittighed

☐ 1 Jeg har dårlig samvittighed over mange ting, jeg har gjort eller burde have gjort

☐ 2 Jeg har dårlig samvittighed det meste af tiden

☐ 3 Jeg plages uafbrudt af dårlig samvittighed

**6.6 Følelser af at blive straffet**

☐ 0 Jeg føler ikke, at jeg bliver straffet

☐ 1 Jeg føler, at jeg kan blive straffet

☐ 2 Jeg forventer at blive straffet

☐ 3 Jeg føler, at jeg bliver straffet

**6.7 Negativ selvfølelse**

☐ 0 Jeg føler mig ikke anderledes omkring mig selv, end jeg hele tiden har gjort

☐ 1 Jeg har mistet min selvtillid

☐ 2 Jeg er trist hele tiden

☐ 3 Jeg kan slet ikke lide mig selv

**6.8 Selvkritik**

☐ 0 Jeg er ikke mere selvkritisk, end jeg plejer

☐ 1 Jeg er mere kritisk overfor mig selv, end jeg plejer

☐ 2 Jeg kritiserer mig selv for alle mine fejl

☐ 3 Jeg giver mig selv skylden for alle dårlige ting, som sker

**6.9 Selvmordstanker**

☐ 0 Jeg har ingen tanker om selvmord

☐ 1 Jeg har tanker om selvmord, men jeg kunne ikke tænke mig at gøre det

☐ 2 Jeg har lyst til at begå selvmord

☐ 3 Jeg ville begå selvmord, hvis lejligheden bød sig

**6.10 Gråd**

☐ 0 Jeg græder ikke mere, end jeg plejer

☐ 1 Jeg græder mere, end jeg plejer

☐ 2 Jeg græder over selv den mindste ting

☐ 3 Jeg har lyst til at græde, men kan ikke

**6.11 Uro**

☐ 0 Jeg føler ikke mere uro, end jeg plejer

☐ 1 Jeg føler mere uro, end jeg plejer

☐ 2 Jeg føler så megen uro, at jeg har svært ved at forholde mig rolig

☐ 3 Jeg føler så megen uro, at jeg er tvunget til hele tiden at bevæge mig eller foretage mig noget

**6.12 Mangel på engagement**

☐ 0 Jeg føler mig ikke anderledes omkring mig selv, end jeg hele tiden har gjort

☐ 1 Jeg er mindre interesseret i mennesker og ting omkring mig, end jeg plejer

☐ 2 Jeg har mistet det meste af min interesse i andre mennesker og ting omkring mig

☐ 3 Det er svært at være engageret i noget som helst

**6.13 Ubeslutsomhed**

☐ 0 Jeg er lige så god til at træffe beslutninger, som jeg plejer

☐ 1 Jeg finder det vanskeligere at træffe beslutninger end tidligere

☐ 2 Det er meget sværere for mig at træffe beslutninger, end det plejer at være

☐ 3 Jeg har svært ved overhovedet at træffe beslutninger

**6.14 Følelse af selvværd**

☐ 0 Jeg føler mig ikke værdiløs

☐ 1 Jeg føler mig ikke så værdifuld og nyttig som tidligere

☐ 2 Jeg føler mig værdiløs, sammenlignet med andre mennesker

☐ 3 Jeg føler mig fuldstændig værdiløs

**6.15 Tab af energi**

☐ 0 Jeg er lige så energisk som altid

☐ 1 Jeg har mindre energi, end jeg plejer

☐ 2 Jeg har ikke energi til at foretage mig ret meget

☐ 3 Jeg har ikke energi til noget som helst

**6.16 Ændringer i søvnvaner**

☐ 0 Jeg har ikke oplevet ændringer i mine søvnvaner

☐ 1a Jeg sover noget MERE, end jeg plejer

☐ 1b Jeg sover noget MINDRE, end jeg plejer

☐ 2a Jeg sover meget MERE, end jeg plejer

☐ 2b Jeg sover meget MINDRE, end jeg plejer

☐ 3a Jeg sover det meste af dagen

☐ 3b Jeg vågner 1-2 timer for tidligt og kan ikke falde i søvn igen

**6.17 Irritabilitet**

☐ 0 Jeg er ikke mere irritabel, end jeg plejer

☐ 1 Jeg er mere irritabel, end jeg plejer

☐ 2 Jeg er meget mere irritabel, end jeg plejer

☐ 3 Jeg er irritabel hele tiden

**6.18 Ændringer i appetit**

☐ 0 Min appetit er uforandret

☐ 1a Jeg har noget MINDRE appetit, end jeg plejer

☐ 1b Jeg har noget MERE appetit, end jeg plejer

☐ 2a Jeg har meget MINDRE appetit, end jeg plejer

☐ 2b Jeg har meget MERE appetit, end jeg plejer

☐ 3a Jeg har slet ingen appetit

☐ 3b Jeg har lyst til mad hele tiden

**6.19 Koncentrationsbesvær**

☐ 0 Jeg er lige så god til at koncentrere mig, som jeg plejer at være

☐ 1 Jeg kan ikke koncentrere mig så godt, som jeg plejer

☐ 2 Det er svært for mig at koncentrere mig om noget ret længe ad gangen

☐ 3 Jeg kan ikke koncentrere mig om noget som helst

**6.20 Træthed og udmattelse**

☐ 0 Jeg er ikke mere træt eller udkørt, end jeg plejer at være

☐ 1 Jeg bliver lettere træt og udkørt end tidligere

☐ 2 Jeg er for træt og udkørt til at gøre mange af de ting, jeg plejer at gøre

☐ 3 Jeg er for træt og udkørt til at gøre det, jeg plejer at gøre

**6.21 Tab for interesse for sex**

☐ 0 Jeg har ikke lagt mærke til nogen ændringer i min interesse for sex

☐ 1 Jeg er mindre interesseret i sex, end jeg plejer

☐ 2 Jeg er meget mindre interesseret i sex nu

☐ 3 Jeg har fuldstændig tabt interessen for sex

☐ 4 Ikke relevant

## Andre psykiske reaktioner

De næste spørgsmål handler om andre psykiske reaktioner, du kan have oplevet i forbindelse med din pårørendes sygdom. Det er vigtigt, at du besvarer alle spørgsmål, selv om du muligvis synes, at nogle af dem ikke passer på din situation.

**I de sidste 4 uger, hvor meget har du været generet af:**

| (Sæt kun ét kryds i hver linje) | Slet ikke ▼ | Lidt ▼ | Noget ▼ | En hel del ▼ | Virkelig meget ▼ |
|---|---|---|---|---|---|
| **7.1** At du pludselig bliver bange uden grund? | ☐ | ☐ | ☐ | ☐ | ☐ |
| **7.2** Nervøsitet eller indre uro? | ☐ | ☐ | ☐ | ☐ | ☐ |
| **7.3** Anfald af rædsel eller panik? | ☐ | ☐ | ☐ | ☐ | ☐ |
| **7.4** At bekymre dig for meget? | ☐ | ☐ | ☐ | ☐ | ☐ |
| **7.5** En følelse af, at du let bliver ærgerlig eller irriteret? | ☐ | ☐ | ☐ | ☐ | ☐ |
| **7.6** Temperaments-udbrud, som du ikke kan kontrollere? | ☐ | ☐ | ☐ | ☐ | ☐ |
| **7.7** At have trang til at slå, såre eller skade nogen? | ☐ | ☐ | ☐ | ☐ | ☐ |
| **7.8** At have trang til at ødelægge eller slå ting i stykker? | ☐ | ☐ | ☐ | ☐ | ☐ |
| **7.9** At komme let i skænderi? | ☐ | ☐ | ☐ | ☐ | ☐ |
| **7.10** At du råber eller smider ting? | ☐ | ☐ | ☐ | ☐ | ☐ |

## Helbredsstatus

Nedenstående spørgsmål drejer sig om, hvordan du oplever dit helbred, da vi ved, at det kan have indflydelse på at håndtere alvorlig sygdom. Det er vigtigt, at du besvarer alle spørgsmål, selv om du muligvis synes, at nogle af dem ikke passer på din situation.

**8.1 Hvordan synes du, dit helbred er alt i alt?** (Sæt kun ét kryds)

| Fremragende ▼ | Vældig godt ▼ | Godt ▼ | Mindre godt ▼ | Dårligt ▼ |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |

**8.2 Sammenlignet med for et år siden, hvordan er dit helbred alt i alt nu?** (Sæt kun ét kryds)

| Meget bedre nu end for et år siden ▼ | Noget bedre nu end for et år siden ▼ | Nogenlunde det samme ▼ | Noget dårligere nu end for et år siden ▼ | Meget dårligere nu end for et år siden ▼ |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |

**8.3 Aktiviteter i hverdagen.**
**Er du på grund af dit helbred begrænset i disse aktiviteter? I så fald, hvor meget?**

| (Sæt kun ét kryds i hver linje) | Ja, meget begrænset ▼ | Ja, lidt begrænset ▼ | Nej, slet ikke ▼ |
|---|---|---|---|
| A. Krævende aktiviteter, som f.eks. at løbe, løfte tunge ting, deltage i anstrengende sport | ☐ | ☐ | ☐ |
| B. Lettere aktiviteter, såsom at flytte et bord, støvsuge eller cykle | ☐ | ☐ | ☐ |
| C. At løfte eller bære dagligvarer | ☐ | ☐ | ☐ |
| D. At gå flere etager op ad trapper | ☐ | ☐ | ☐ |
| E. At gå en etage op ad trapper | ☐ | ☐ | ☐ |
| F. At bøje sig ned eller gå ned i knæ | ☐ | ☐ | ☐ |
| G. Gå mere end en kilometer | ☐ | ☐ | ☐ |
| H. Gå nogle hundrede meter | ☐ | ☐ | ☐ |
| I. Gå 100 meter | ☐ | ☐ | ☐ |
| J. Gå i bad eller tage tøj på | ☐ | ☐ | ☐ |

**8.4 Har du inden for de sidste 4 uger, haft nogen af følgende problemer med dit arbejde eller andre daglige aktiviteter på grund af dit fysiske helbred?**

| (Sæt kun ét kryds i hver linje) | Ja ▼ | Nej ▼ |
|---|---|---|
| A. Jeg har skåret ned på den tid, jeg bruger på arbejde eller andre aktiviteter | ☐ | ☐ |
| B. Jeg har nået mindre, end jeg gerne ville | ☐ | ☐ |
| C. Jeg har været begrænset i, hvilken slags arbejde eller andre aktiviteter jeg har kunnet udføre | ☐ | ☐ |
| D. Jeg har haft besvær med at udføre mit arbejde eller andre aktiviteter (f.eks. krævede det en ekstra indsats) | ☐ | ☐ |

**8.5 Har du inden for de seneste 4 uger haft nogen af følgende problemer med dit arbejde eller andre daglige aktiviteter på grund af følelsesmæssige problemer?**

| (Sæt kun ét kryds i hver linje) | Ja ▼ | Nej ▼ |
|---|---|---|
| A. Jeg har skåret ned på den tid, jeg bruger på arbejde eller andre aktiviteter | ☐ | ☐ |
| B. Jeg har nået mindre, end jeg gerne ville | ☐ | ☐ |
| C. Jeg har været begrænset i, hvilken slags arbejde eller andre aktiviteter jeg har kunnet udføre | ☐ | ☐ |

**8.6 Inden for de sidste 4 uger hvor meget har dit fysiske helbred eller følelsesmæssige problemer vanskeliggjort din kontakt med familie, venner, naboer eller andre?** (Sæt kun ét kryds)

| Slet ikke ▼ | Lidt ▼ | Noget ▼ | En hel del ▼ | Virkelig meget ▼ |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |

**8.7 Hvor stærke fysiske smerter har du haft i de sidste 4 uger?** (Sæt kun ét kryds)

| Ingen smerter ▼ | Meget lette smerter ▼ | Lette smerter ▼ | Middelstærke smerter ▼ | Stærke smerter ▼ | Meget stærke smerter ▼ |
|---|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**8.8 Inden for de sidste 4 uger hvor meget har fysisk smerte vanskeliggjort dit daglige arbejde (både arbejde uden for hjemmet og husarbejde)?** (Sæt kun ét kryds)

| Slet ikke ▼ | Lidt ▼ | Noget ▼ | En hel del ▼ | Virkelig meget ▼ |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |

**8.9 Disse spørgsmål handler om, hvordan du har haft det i de sidste 4 uger. Hvor stor en del af tiden i de sidste 4 uger:**

| (Sæt kun ét kryds i hver linje) | Hele tiden ▼ | Det meste af tiden ▼ | En hel del af tiden ▼ | Noget af tiden ▼ | Lidt af tiden ▼ | På intet tidspunkt ▼ |
|---|---|---|---|---|---|---|
| A Har du følt dig veloplagt og fuld af liv? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| B Har du været meget nervøs? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| C Har du været så langt nede, at intet kunne muntre dig op? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| D Har du følt dig rolig og afslappet? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| E Har du været fuld af energi? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| F Har du følt dig trist til mode? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| G Har du følt dig udslidt? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| H Har du været glad og tilfreds? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| I Har du følt dig træt? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**8.10 Inden for de sidste 4 uger, hvor stor en del af tiden har dit fysiske helbred eller følelsesmæssige problemer gjort det vanskeligt at se andre mennesker (f.eks. besøge venner, slægtninge osv.)?** (Sæt kun ét kryds)

| Hele tiden ▼ | Det meste af tiden ▼ | Noget af tiden ▼ | Lidt af tiden ▼ | På intet tidspunkt ▼ |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |

**8.11 Hvor rigtige eller forkerte er de følgende udsagn for dit vedkommende?**

| (Sæt kun ét kryds i hver linje) | Helt rigtigt ▼ | Overvejende rigtigt ▼ | Ved ikke ▼ | Overvejende forkert ▼ | Helt forkert ▼ |
|---|---|---|---|---|---|
| A Jeg bliver nok lettere syg end andre | ☐ | ☐ | ☐ | ☐ | ☐ |
| B Jeg er lige så rask som enhver anden, jeg kender | ☐ | ☐ | ☐ | ☐ | ☐ |
| C Jeg forventer, at mit helbred bliver dårligere | ☐ | ☐ | ☐ | ☐ | ☐ |
| D Mit helbred er fremragende | ☐ | ☐ | ☐ | ☐ | ☐ |

## Fremtiden

Nu kommer der nogle spørgsmål om dine tanker om fremtiden og den information, I har fået herom fra læger (på sygehuset og/eller hos din pårørendes egen læge). Vi håber ikke, at spørgsmålene virker stødende, og du kan naturligvis undlade at svare på disse spørgsmål, hvis du har det bedst med det.

**9.1 Hvor meget information har du og din pårørende fået fra lægerne om ...**

| (Sæt kun ét kryds i hver linje) | For meget ▼ | Passende ▼ | Ikke nok ▼ | Ingen ▼ | Ved ikke/ikke relevant ▼ |
|---|---|---|---|---|---|
| A ... fremtidsudsigterne for din pårørendes sygdom? | ☐ | ☐ | ☐ | ☐ | ☐ |
| B ... din pårørendes risiko for at dø af sin sygdom? | ☐ | ☐ | ☐ | ☐ | ☐ |

**9.2 I hvor høj grad ...**

| (Sæt kun ét kryds i hver linje) | I høj grad ▼ | I nogen grad ▼ | I mindre grad ▼ | Slet ikke ▼ | Ved ikke/ikke relevant ▼ |
|---|---|---|---|---|---|
| A ... føler du dig forberedt på, at din pårørende kan dø af sygdommen? | ☐ | ☐ | ☐ | ☐ | ☐ |
| B ... har I sørget for praktiske eller økonomiske forberedelser i forbindelse med, at din pårørende kan dø af sygdommen? | ☐ | ☐ | ☐ | ☐ | ☐ |

**9.3 Har din pårørende haft en samtale med sundhedspersonale angående sine ønsker for den sidste tid?** (Sæt kun ét kryds)

☐ Ja ☐ Nej ☐ Ved ikke

**9.4 Hvor meget fylder tanken hos dig om, at din pårørende kan dø af sin sygdom?** (Sæt kun ét kryds)

| Jeg undlader at tænke på det ▼ | Jeg tænker næsten ikke på det ▼ | Jeg tænker ofte på det ▼ | Jeg tænker på det hele tiden ▼ | Ved ikke/ ikke relevant ▼ |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |

## Kommunikation

Det følgende drejer sig om, hvor meget du og din pårørende snakker om sygdommen og fremtiden. Vi håber ikke, at spørgsmålene virker stødende, og du kan naturligvis undlade at svare på disse spørgsmål, hvis du har det bedst med det.

**10.1 I hvor høj grad mener du, at følgende udsagn passer på jeres situation?**

| (Sæt kun ét kryds i hver linje) | Passer i meget høj grad ▼ | Passer i høj grad ▼ | Passer i nogen grad ▼ | Passer i mindre grad ▼ | Passer slet ikke ▼ |
|---|---|---|---|---|---|
| A Jeg snakker næsten ikke med min pårørende om sygdommen, fordi jeg ikke vil gøre ham/hende ked af det | ☐ | ☐ | ☐ | ☐ | ☐ |
| B Jeg er bange for at snakke med min pårørende om risikoen for, at jeg skal leve videre uden ham/hende | ☐ | ☐ | ☐ | ☐ | ☐ |
| C Jeg ved ikke, hvad jeg skal gøre eller sige, når min pårørende lider og har det dårligt | ☐ | ☐ | ☐ | ☐ | ☐ |
| D Jeg undgår at snakke med min pårørende om hans/hendes følelser og bekymringer | ☐ | ☐ | ☐ | ☐ | ☐ |
| E Jeg undgår at snakke med min pårørende om, at han/hun er i risiko for at dø | ☐ | ☐ | ☐ | ☐ | ☐ |

**10.2 Hvis du har kommentarer til udfyldelsen af de ovenstående 5 spørgsmål, er du velkommen til at skrive dem her (der er plads til generelle kommentarer til sidst i spørgeskemaet):**

Forbeholdt kodning ☐☐

________________________________________________

________________________________________________

________________________________________________

________________________________________________

---

## Opholdssted

Vi ved, at mange mennesker på et eller andet tidspunkt gør sig tanker om deres sidste tid. Der kommer nu nogle spørgsmål omkring dette. Vi håber ikke, at spørgsmålene virker stødende, og du kan naturligvis undlade at svare, hvis du har det bedst med det.

**11.1 Har du talt med din pårørende om, hvor han/hun foretrækker at være i sin sidste tid** (med sidste tid menes de sidste dage/uger af din pårørendes liv)**?**

☐ Ja ☐ Nej ☐ Ved ikke ☐ Ønsker ikke at svare

**Hvis ja, hvor?**

- ☐ Hjemme hos sig selv
- ☐ Hjemme hos en pårørende. Hvem? ______________________________ Forbeholdt kodning ☐☐
- ☐ Fast bolig på plejehjem/beskyttet bolig
- ☐ Aflastningsplads på plejehjem
- ☐ Hospital
- ☐ Hospice
- ☐ Andet sted, anfør venligst hvilket: ______________________________ Forbeholdt kodning ☐☐
- ☐ Ved ikke/uafklaret

**11.2 Har du overvejet, hvor du kunne tænke dig, at din pårørende skal være i hans/hendes sidste tid** (med sidste tid menes de sidste dage/uger af din pårørendes liv)**?**

☐ Ja ☐ Nej ☐ Ved ikke ☐ Ønsker ikke at svare

**Hvis ja, hvor?**

- ☐ Hjemme hos sig selv
- ☐ Hjemme hos en pårørende. Hvem? ______________________________ Forbeholdt kodning ☐☐
- ☐ Fast bolig på plejehjem/beskyttet bolig
- ☐ Aflastningsplads på plejehjem
- ☐ Hospital
- ☐ Hospice
- ☐ Andet sted, anfør venligst hvilket: ______________________________ Forbeholdt kodning ☐☐
- ☐ Ved ikke/uafklaret

## Afslutning

Du er nu færdig med at udfylde spørgeskemaet. Det vil være en stor hjælp, hvis du vil kontrollere, at du ikke er kommet til at springe spørgsmål over i skemaet.

**Du er meget velkommen til at skrive kommentarer, erfaringer eller tanker i forbindelse med at være pårørende til en alvorligt syg:**

Forbeholdt kodning ☐☐

Du bedes sende os det udfyldte spørgeskema i den vedlagte frankerede svarkuvert.

**Mange tak for din hjælp!**

# Appendix C: Invitation letter for caregivers at follow-up

Aarhus Universitetshospital

FORSKNINGSENHEDEN
FOR ALMEN PRAKSIS
Århus

xx-xx-201x/lbnr

**Kære –Pårørende-**

## Opfølgning på din deltagelse i undersøgelsen ”At være pårørende…”

Vi vil gerne sige dig mange tak for din deltagelse i spørgeskemaundersøgelsen ”At være pårørende…”. Den opfølgende del af undersøgelsen sætter fokus på pårørende, der har mistet. Vi kan se, at du mistede *–PT NAVN-* for godt et halvt år siden. Det har uden tvivl været en tid med forandringer, og vi vil derfor meget gerne vide, hvordan du har det nu. Undersøgelsens formål er at blive klogere på pårørendes behov for hjælp, således at den enkelte fremover kan få den bedst mulige støtte fra sundhedsvæsenet i forbindelse med alvorlig sygdom.

### Hvad beder vi dig om?

Vi håber, at du endnu en gang vil tage dig tid til at udfylde vedlagte spørgeskema. Du vil måske kunne genkende nogle spørgsmål fra det første spørgeskema. Du bedes besvare alle spørgsmål igen, ud fra hvordan du har det nu. Det tager ca. 40 min., og du bedes returnere skemaet i den frankerede svarkuvert. Det er helt i orden at få hjælp til udfyldelsen af en nærtstående og at holde pauser undervejs.
Har du har spørgsmål eller kommentarer, er du velkommen til at ringe eller skrive til den projektansvarlige, læge Mette Kjærgaard Nielsen på telefonnummer: 28 92 34 02 eller e-mail: mette.nielsen@alm.au.dk.

### Fortrolighed

Alle informationer behandles strengt fortroligt. Kun forskergruppen får adgang til at se din besvarelse. Undersøgelsen er godkendt af Datatilsynet og er forelagt Den Videnskabsetiske Komité.

For at kunne forbedre sundhedsvæsenets indsats fremover er det vigtigt, at så mange som muligt deltager. Vi håber derfor, at du vil tage dig tid til at udfylde spørgeskemaet, så dine svar kan indgå i undersøgelsen.

**Mange tak for din hjælp!**

**Venlig hilsen**

Mette Kjærgaard Nielsen

Mette Kjærgaard Nielsen
Projektansvarlig, læge
Forskningsenheden for Almen Praksis, Aarhus

Mai-Britt Guldin
Psykolog, ph.d.
Det Palliative Team, Aarhus Universitetshospital

Flemming Bro
Forskningsleder, professor, dr.med.
Forskningsenheden for Almen Praksis, Aarhus

Anders Bonde Jensen
Overlæge, ph.d.
Onkologisk Afdeling, Aarhus Universitetshospital

## Appendix D: Questionnaire to caregivers at follow-up

# At være pårørende...

## Opfølgende spørgeskema til pårørende, der har mistet

Forskningsenheden for Almen Praksis
Aarhus Universitet

Aarhus Universitetshospital

At være pårørende...

Forskningsenheden for Almen Praksis
Aarhus Universitet
Bartholins Allé 2
8000 Aarhus C

## Indledende oplysninger

Indledningsvis kommer der nogle spørgsmål om den sidste tid i din pårørendes sygdomsforløb og om, hvor døden indtrådte.

**1.1** **Dato for udfyldelse af spørgeskemaet:**

☐☐ - ☐☐ - 201☐
Dag Måned År

**1.2** **Har du haft officiel plejeorlov under din pårørendes sygdomsforløb?**

☐ Ja, jeg har haft plejeorlov med økonomisk kompensation: Fuldtid? ☐ Deltid? ☐
☐ Anden orlov, f.eks. taget fri eller været sygemeldt: Fuldtid? ☐ Deltid? ☐
☐ Nej, jeg har ikke haft orlov
☐ Ikke relevant, da jeg ikke er på arbejdsmarkedet

**1.3** **I forhold til din pårørendes sidste uger:**

| (Sæt kun ét kryds i hver linje) | 0-2 timer | 3-8 timer | 9-16 timer | 17-24 timer |
|---|---|---|---|---|
| A Hvor meget var du tilstede hos din pårørende pr. døgn? | ☐ | ☐ | ☐ | ☐ |
| B Hvor meget tid brugte du på pleje og praktisk hjælp til din pårørende pr. døgn? | ☐ | ☐ | ☐ | ☐ |

**1.4** **Hvor døde din pårørende?** (Sæt kun ét kryds)

☐ Hjemme hos sig selv
☐ Hjemme hos en pårørende. Angiv gerne hos hvem: ______________________________
☐ Fast bolig på plejehjem/i plejebolig/beskyttet bolig/ældrebolig
☐ Aflastningsplads på plejehjem
☐ Hospital
☐ Hospice
☐ Andet sted, anfør venligst hvilket: ____________________________________________

**1.5** **Hvor foretrak din pårørende at dø?** (Sæt kun ét kryds)

☐ Hjemme hos sig selv
☐ Hjemme hos en pårørende. Angiv gerne hos hvem: ____________________________
☐ Fast bolig på plejehjem/i plejebolig/beskyttet bolig/ældrebolig
☐ Aflastningsplads på plejehjem
☐ Hospital
☐ Hospice
☐ Andet sted, anfør venligst hvilket: ___________________________________________
☐ Ved ikke

**1.6** **Når omstændighederne var sådan, at din pårørende skulle dø, hvor ville du så gerne have, at han/hun døde henne?** (Sæt kun ét kryds)

☐ Hjemme hos sig selv
☐ Hjemme hos en pårørende. Angiv gerne hos hvem: ____________________________
☐ Fast bolig på plejehjem/i plejebolig/beskyttet bolig/ældrebolig
☐ Aflastningsplads på plejehjem
☐ Hospital
☐ Hospice
☐ Andet sted, anfør venligst hvilket: ___________________________________________
☐ Ved ikke

**1.7** **I hvor høj grad beskriver nedenstående ord selve dødsfaldet?**

| (Sæt kun ét kryds i hver linje) | I høj grad | I nogen grad | I mindre grad | Slet ikke | Ved ikke |
|---|---|---|---|---|---|
| A Dramatisk/voldsomt? | ☐ | ☐ | ☐ | ☐ | ☐ |
| B Stille og roligt? | ☐ | ☐ | ☐ | ☐ | ☐ |
| C Langtrukkent? | ☐ | ☐ | ☐ | ☐ | ☐ |
| D Pludseligt? | ☐ | ☐ | ☐ | ☐ | ☐ |

**1.8** **Har du tidligere i livet oplevet et betydningsfuldt tab af følgende pårørende?** (Sæt evt. flere krydser)

☐ Ja, en ægtefælle eller en samlever
☐ Ja, en kæreste, som du ikke boede sammen med
☐ Ja, et barn
☐ Ja, en forælder
☐ Ja, en anden nær pårørende. Angiv gerne hvem: _______________________________
☐ Nej

## Forberedelser

Nu kommer der nogle spørgsmål om jeres eventuelle forberedelser forud for din pårørendes død og om den information, I fik fra lægerne (på hospitalet og/eller hos din pårørendes egen læge).

**2.1** **Hvor meget information fik du og din pårørende fra lægerne om …**

| (Sæt kun ét kryds i hver linje) | For meget | Passende | Ikke nok | Ingen | Ved ikke/ ikke relevant |
|---|---|---|---|---|---|
| A at din pårørende var uhelbredeligt syg? | ☐ | ☐ | ☐ | ☐ | ☐ |
| B at din pårørende ville dø af sin sygdom? | ☐ | ☐ | ☐ | ☐ | ☐ |

**2.2** **Havde din pårørende en samtale i forløbet med sundhedspersonale angående sine ønsker for den sidste tid?** (Sæt kun ét kryds)

☐ Ja ☐ Nej ☐ Ved ikke

**2.3** **I hvor høj grad …**

| (Sæt kun ét kryds i hver linje) | I høj grad | I nogen grad | I mindre grad | Slet ikke | Ved ikke/ ikke relevant |
|---|---|---|---|---|---|
| A var du forberedt på, at din pårørende ville dø af sygdommen? | ☐ | ☐ | ☐ | ☐ | ☐ |
| B havde I sørget for praktiske eller økonomiske forberedelser inden din pårørendes dødsfald? | ☐ | ☐ | ☐ | ☐ | ☐ |

**2.4** **Hvornår indså du med din <u>fornuft</u>, at din pårørende ville dø af sin sygdom?** (Sæt kun ét kryds)

☐ Jeg blev ikke klar over det, før det skete
☐ Under 24 timer før min pårørende døde
☐ Mellem 2 og 30 dage før min pårørende døde
☐ Mellem 1 og 3 måneder før min pårørende døde
☐ Mellem 3 og 6 måneder før min pårørende døde
☐ Mellem 6 og 12 måneder før min pårørende døde
☐ Mere end 1 år før min pårørende døde
☐ Jeg kan ikke tidsfæste det

**2.5** **Hvornår indså du <u>følelsesmæssigt</u>, at din pårørende ville dø af sin sygdom?** (Sæt kun ét kryds)

☐ Jeg blev ikke klar over det, før det skete
☐ Under 24 timer før min pårørende døde
☐ Mellem 2 og 30 dage før min pårørende døde
☐ Mellem 1 og 3 måneder før min pårørende døde
☐ Mellem 3 og 6 måneder før min pårørende døde
☐ Mellem 6 og 12 måneder før min pårørende døde
☐ Mere end 1 år før min pårørende døde
☐ Jeg kan ikke tidsfæste det

**2.6** **I hvor høj grad mener du, at følgende udsagn passer på jeres situation i din pårørendes sidste tid?**

| (Sæt kun ét kryds i hver linje) | Passer i meget høj grad | Passer i høj grad | Passer i nogen grad | Passer i mindre grad | Passer slet ikke |
|---|---|---|---|---|---|
| A Jeg snakkede næsten ikke med min pårørende om hans/hendes sygdom, fordi jeg ikke ville gøre ham/hende ked af det | ☐ | ☐ | ☐ | ☐ | ☐ |
| B Jeg var bange for at snakke med min pårørende om, at jeg skulle leve videre uden ham/hende | ☐ | ☐ | ☐ | ☐ | ☐ |
| C Jeg vidste ikke, hvad jeg skulle gøre eller sige, når min pårørende led og havde det dårligt | ☐ | ☐ | ☐ | ☐ | ☐ |
| D Jeg undgik at snakke med min pårørende om hans/hendes følelser og bekymringer | ☐ | ☐ | ☐ | ☐ | ☐ |
| E Jeg undgik at snakke med min pårørende om, at han/hun snart skulle dø | ☐ | ☐ | ☐ | ☐ | ☐ |
| F Jeg snakkede ikke med min pårørende om sygdom og død, fordi han/hun ikke ønskede at snakke om det. | ☐ | ☐ | ☐ | ☐ | ☐ |

## Reaktioner på det at miste

Nedenstående handler om de reaktioner, man kan have, efter at have mistet en pårørende.

**Inden for den seneste måned, hvor ofte har du ...**

| (Sæt kun ét kryds i hver linje) | Slet ikke | Mindst én gang | Mindst en gang om ugen | Mindst en gang om dagen | Flere gange om dagen |
|---|---|---|---|---|---|
| **3.1** ... følt savn eller længsel efter den person, du har mistet? | ☐ | ☐ | ☐ | ☐ | ☐ |
| **3.2** ... oplevet pludselig at blive grebet af en intens følelsesmæssig smerte eller sorg, som har at gøre med den person, du har mistet? | ☐ | ☐ | ☐ | ☐ | ☐ |

**3.3** **Tænk på spørgsmål 3.1 og 3.2 ovenfor: Har du haft de beskrevne følelser mindst en gang om dagen i en periode på mindst 6 måneder?**

☐ Nej ☐ Ja

**Inden for den seneste måned, hvor ofte har du ...**

| (Sæt kun ét kryds i hver linje) | Slet ikke | Mindst én gang | Mindst en gang om ugen | Mindst en gang om dagen | Flere gange om dagen |
|---|---|---|---|---|---|
| **3.4** ... forsøgt at undgå at blive mindet om, at den person, du har mistet, er borte? | ☐ | ☐ | ☐ | ☐ | ☐ |
| **3.5** ... følt dig lamslået, chokeret eller ved siden af dig selv på grund af dit tab? | ☐ | ☐ | ☐ | ☐ | ☐ |

**Besvar hvert spørgsmål ved at sætte kryds ved det svar, som passer bedst på, hvordan du har det lige nu.**

| (Sæt kun ét kryds i hver linje) | Slet ikke | Lidt | Noget | En hel del | Virkelig meget |
|---|---|---|---|---|---|
| **3.6** Føler du dig usikker på din rolle i livet, eller har du det som om, du ikke ved, hvem du er (dvs. en følelse af, at en del af dig er død)? | ☐ | ☐ | ☐ | ☐ | ☐ |

**Besvar hvert spørgsmål ved at sætte kryds ved det svar, som passer bedst på, hvordan du har det lige nu.**

| (Sæt kun ét kryds i hver linje) | Slet ikke | Lidt | Noget | En hel del | Virkelig meget |
|---|---|---|---|---|---|
| **3.7** Har du haft svært ved at acceptere dit tab? | ☐ | ☐ | ☐ | ☐ | ☐ |
| **3.8** Har det været svært for dig at have tillid til andre siden dit tab? | ☐ | ☐ | ☐ | ☐ | ☐ |
| **3.9** Føler du bitterhed over dit tab? | ☐ | ☐ | ☐ | ☐ | ☐ |
| **3.10** Oplever du, at det er svært for dig at komme videre (f.eks. at få nye venner, finde nye interesser)? | ☐ | ☐ | ☐ | ☐ | ☐ |
| **3.11** Føler du dig følelsesmæssigt lammet efter dit tab? | ☐ | ☐ | ☐ | ☐ | ☐ |
| **3.12** Føler du, at livet er utilfredsstillende, tomt eller meningsløst efter dit tab? | ☐ | ☐ | ☐ | ☐ | ☐ |

**3.13** **Har du oplevet en betydelig nedsættelse af din funktionsevne på sociale, arbejdsrelaterede eller andre væsentlige områder (f.eks. huslige pligter og daglige gøremål)?** (Sæt kun ét kryds)

☐ Nej ☐ Ja

For nogle pårørende kan dødsfaldet ud over sorg også give anledning til mere blandede følelser eller måske positive oplevelser.

**3.14** **Kan du genkende nogle af de nedenstående tanker, følelser eller oplevelser i forbindelse med din pårørendes dødsfald?** (Sæt evt. flere krydser)

- ☐ Accept
- ☐ Afklarethed i forhold til at din pårørende skulle dø
- ☐ Sorgen gør ondt, men mindre end jeg havde forventet
- ☐ Døden er en naturlig del af livet
- ☐ Taknemmelighed, f.eks. over at have haft en god tid sammen med din pårørende
- ☐ Lettelse, f.eks. fordi din pårørende fik fred
- ☐ Tilfredshed med den måde sygdommen og den sidste tid forløb på
- ☐ Ro i sindet
- ☐ Større bevidsthed om at sætte pris på livet
- ☐ Andet: ____________________
- ☐ Nej/ikke relevant

## Følelsesmæssig reaktion

Nedenstående udsagn handler om din følelsesmæssige reaktion efter dødsfaldet, og hvordan det påvirker dig nu.

**Læs venligst hver gruppe af udsagn grundigt og vælg det udsagn i hver gruppe, der bedst beskriver, hvordan du har følt det de seneste 2 uger.** (Sæt kun ét kryds i hvert spørgsmål)

4.1 **Tristhed**

☐ 0 Jeg føler mig ikke trist
☐ 1 Jeg er ofte trist
☐ 2 Jeg er trist hele tiden
☐ 3 Jeg er så trist og ked af det, at jeg ikke kan holde det ud

4.2 **Pessimisme**

☐ 0 Jeg er ikke bekymret for min fremtid
☐ 1 Jeg er mere bekymret for min fremtid, end jeg plejer
☐ 2 Jeg forventer, at min fremtid vil udvikle sig i negativ retning
☐ 3 Jeg føler, at fremtiden er håbløs, og at det kun kan blive værre

4.3 **Tidligere nederlag**

☐ 0 Jeg føler mig ikke mislykket
☐ 1 Jeg har klaret mig dårligere, end jeg burde
☐ 2 Jeg har mange nederlag bag mig
☐ 3 Jeg føler mig som en total fiasko

4.4 **Manglende glæde**

☐ 0 Jeg oplever lige så stor glæde ved tilværelsen, som jeg plejer
☐ 1 Jeg glæder mig ikke så meget over tilværelsen, som jeg plejer
☐ 2 Jeg har meget lidt fornøjelse af de ting, jeg tidligere kunne glæde mig over
☐ 3 Jeg har slet ingen fornøjelse af det, jeg tidligere kunne glæde mig over

4.5 **Skyldfølelse**

☐ 0 Jeg plages ikke specielt af dårlig samvittighed
☐ 1 Jeg har dårlig samvittighed over mange ting, jeg har gjort eller burde have gjort
☐ 2 Jeg har dårlig samvittighed det meste af tiden
☐ 3 Jeg plages uafbrudt af dårlig samvittighed

4.6 **Følelser af at blive straffet**

☐ 0 Jeg føler ikke, at jeg bliver straffet
☐ 1 Jeg føler, at jeg kan blive straffet
☐ 2 Jeg forventer at blive straffet
☐ 3 Jeg føler, at jeg bliver straffet

4.7 **Negativ selvfølelse**

☐ 0 Jeg føler mig ikke anderledes omkring mig selv, end jeg hele tiden har gjort
☐ 1 Jeg har mistet min selvtillid
☐ 2 Jeg er trist hele tiden
☐ 3 Jeg kan slet ikke lide mig selv

4.8 **Selvkritik**

☐ 0 Jeg er ikke mere selvkritisk, end jeg plejer
☐ 1 Jeg er mere kritisk overfor mig selv, end jeg plejer
☐ 2 Jeg kritiserer mig selv for alle mine fejl
☐ 3 Jeg giver mig selv skylden for alle dårlige ting, som sker

4.9 **Selvmordstanker**

☐ 0 Jeg har ingen tanker om selvmord
☐ 1 Jeg har tanker om selvmord, men jeg kunne ikke tænke mig at gøre det
☐ 2 Jeg har lyst til at begå selvmord
☐ 3 Jeg ville begå selvmord, hvis lejligheden bød sig

4.10 **Gråd**

☐ 0 Jeg græder ikke mere, end jeg plejer
☐ 1 Jeg græder mere, end jeg plejer
☐ 2 Jeg græder over selv den mindste ting
☐ 3 Jeg har lyst til at græde, men kan ikke

4.11 **Uro**

☐ 0 Jeg føler ikke mere uro, end jeg plejer
☐ 1 Jeg føler mere uro, end jeg plejer
☐ 2 Jeg føler så megen uro, at jeg har svært ved at forholde mig rolig
☐ 3 Jeg føler så megen uro, at jeg er tvunget til hele tiden at bevæge mig eller foretage mig noget

4.12 **Mangel på engagement**

☐ 0 Jeg føler mig ikke anderledes omkring mig selv, end jeg hele tiden har gjort
☐ 1 Jeg er mindre interesseret i mennesker og ting omkring mig, end jeg plejer
☐ 2 Jeg har mistet det meste af min interesse i andre mennesker og ting omkring mig
☐ 3 Det er svært at være engageret i noget som helst

4.13 **Ubeslutsomhed**

☐ 0 Jeg er lige så god til at træffe beslutninger, som jeg plejer
☐ 1 Jeg finder det vanskeligere at træffe beslutninger end tidligere
☐ 2 Det er meget sværere for mig at træffe beslutninger, end det plejer at være
☐ 3 Jeg har svært ved overhovedet at træffe beslutninger

**4.14** **Følelse af selvværd**

☐ 0 Jeg føler mig ikke værdiløs
☐ 1 Jeg føler mig ikke så værdifuld og nyttig som tidligere
☐ 2 Jeg føler mig værdiløs, sammenlignet med andre mennesker
☐ 3 Jeg føler mig fuldstændig værdiløs

**4.15** **Tab af energi**

☐ 0 Jeg er lige så energisk som altid
☐ 1 Jeg har mindre energi, end jeg plejer
☐ 2 Jeg har ikke energi til at foretage mig ret meget
☐ 3 Jeg har ikke energi til noget som helst

**4.16** **Ændringer i søvnvaner**

☐ 0 Jeg har ikke oplevet ændringer i mine søvnvaner
☐ 1a Jeg sover noget MERE, end jeg plejer
☐ 1b Jeg sover noget MINDRE, end jeg plejer
☐ 2a Jeg sover meget MERE, end jeg plejer
☐ 2b Jeg sover meget MINDRE, end jeg plejer
☐ 3a Jeg sover det meste af dagen
☐ 3b Jeg vågner 1-2 timer for tidligt og kan ikke falde i søvn igen

**4.17** **Irritabilitet**

☐ 0 Jeg er ikke mere irritabel, end jeg plejer
☐ 1 Jeg er mere irritabel, end jeg plejer
☐ 2 Jeg er meget mere irritabel, end jeg plejer
☐ 3 Jeg er irritabel hele tiden

**4.18** **Ændringer i appetit**

☐ 0 Min appetit er uforandret
☐ 1a Jeg har noget MINDRE appetit, end jeg plejer
☐ 1b Jeg har noget MERE appetit, end jeg plejer
☐ 2a Jeg har meget MINDRE appetit, end jeg plejer
☐ 2b Jeg har meget MERE appetit, end jeg plejer
☐ 3a Jeg har slet ingen appetit
☐ 3b Jeg har lyst til mad hele tiden

**4.19** **Koncentrationsbesvær**

☐ 0 Jeg er lige så god til at koncentrere mig, som jeg plejer at være
☐ 1 Jeg kan ikke koncentrere mig så godt, som jeg plejer
☐ 2 Det er svært for mig at koncentrere mig om noget ret længe ad gangen
☐ 3 Jeg kan ikke koncentrere mig om noget som helst

**4.20** **Træthed og udmattelse**

☐ 0 Jeg er ikke mere træt eller udkørt, end jeg plejer at være
☐ 1 Jeg bliver lettere træt og udkørt end tidligere
☐ 2 Jeg er for træt og udkørt til at gøre mange af de ting, jeg plejer at gøre
☐ 3 Jeg er for træt og udkørt til at gøre det, jeg plejer at gøre

**4.21** **Tab af interesse for sex**

☐ 0 Jeg har ikke lagt mærke til nogen ændringer i min interesse for sex
☐ 1 Jeg er mindre interesseret i sex, end jeg plejer
☐ 2 Jeg er meget mindre interesseret i sex nu
☐ 3 Jeg har fuldstændig tabt interessen for sex
☐ 4 Ikke relevant

## Andre psykiske reaktioner

De næste spørgsmål vedrører andre psykiske reaktioner, du kan have oplevet efter dødsfaldet.

**I de sidste 4 uger, hvor meget har du været generet af ...**

| (Sæt kun ét kryds i hver linje) | Slet ikke | Lidt | Noget | En hel del | Virkelig meget |
|---|---|---|---|---|---|
| **5.1** at du pludselig bliver bange uden grund? | ☐ | ☐ | ☐ | ☐ | ☐ |
| **5.2** nervøsitet eller indre uro? | ☐ | ☐ | ☐ | ☐ | ☐ |
| **5.3** anfald af rædsel eller panik? | ☐ | ☐ | ☐ | ☐ | ☐ |
| **5.4** at bekymre dig for meget? | ☐ | ☐ | ☐ | ☐ | ☐ |
| **5.5** en følelse af, at du let bliver ærgerlig eller irriteret? | ☐ | ☐ | ☐ | ☐ | ☐ |
| **5.6** temperamentsudbrud, som du ikke kan kontrollere? | ☐ | ☐ | ☐ | ☐ | ☐ |
| **5.7** at have trang til at slå, såre eller skade nogen? | ☐ | ☐ | ☐ | ☐ | ☐ |
| **5.8** at have trang til at ødelægge eller slå ting i stykker? | ☐ | ☐ | ☐ | ☐ | ☐ |
| **5.9** at komme let i skænderi? | ☐ | ☐ | ☐ | ☐ | ☐ |
| **5.10** at du råber eller smider med ting? | ☐ | ☐ | ☐ | ☐ | ☐ |

## Helbredsstatus

Nedenstående spørgsmål drejer sig om, hvordan du oplever dit eget helbred.

**6.1 Hvordan synes du, dit helbred er alt i alt?** (Sæt kun ét kryds)

| Fremragende | Vældig godt | Godt | Mindre godt | Dårligt |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |

**6.2 Sammenlignet med for et år siden, hvordan er dit helbred alt i alt nu?** (Sæt kun ét kryds)

| Meget bedre end for et år siden | Noget bedre end for et år siden | Nogenlunde det samme | Noget dårligere end for et år siden | Meget dårligere end for et år siden |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |

**6.3 Aktiviteter i hverdagen. Er du på grund af dit helbred begrænset i disse aktiviteter? I så fald, hvor meget?**

| (Sæt kun ét kryds i hver linje) | Ja, meget begrænset | Ja, lidt begrænset | Nej, slet ikke begrænset |
|---|---|---|---|
| A Krævende aktiviteter som f.eks. at løbe, løfte tunge ting, deltage i anstrengende sport | ☐ | ☐ | ☐ |
| B Lettere aktiviteter såsom at flytte et bord, støvsuge eller cykle | ☐ | ☐ | ☐ |
| C At løfte eller bære dagligvarer | ☐ | ☐ | ☐ |
| D At gå flere etager op ad trapper | ☐ | ☐ | ☐ |
| E At gå en etage op ad trapper | ☐ | ☐ | ☐ |
| F At bøje sig ned eller gå ned i knæ | ☐ | ☐ | ☐ |
| G At gå mere end en kilometer | ☐ | ☐ | ☐ |
| H At gå nogle hundrede meter | ☐ | ☐ | ☐ |
| I At gå 100 meter | ☐ | ☐ | ☐ |
| J At gå i bad eller tage tøj på | ☐ | ☐ | ☐ |

**6.4 Har du inden for de sidste 4 uger, haft nogen af følgende problemer med dit arbejde eller andre daglige aktiviteter på grund af dit fysiske helbred?**

| (Sæt kun ét kryds i hver linje) | Ja | Nej |
|---|---|---|
| A Jeg har skåret ned på den tid, jeg bruger på arbejde eller andre aktiviteter | ☐ | ☐ |
| B Jeg har nået mindre, end jeg gerne ville | ☐ | ☐ |
| C Jeg har været begrænset i, hvilken slags arbejde eller andre aktiviteter jeg har kunnet udføre | ☐ | ☐ |
| D Jeg har haft besvær med at udføre mit arbejde eller andre aktiviteter (f.eks. krævede det en ekstra indsats) | ☐ | ☐ |

**6.5 Har du inden for de seneste 4 uger haft nogen af følgende problemer med dit arbejde eller andre daglige aktiviteter på grund af følelsesmæssige problemer?**

| (Sæt kun ét kryds i hver linje) | Ja | Nej |
|---|---|---|
| A Jeg har skåret ned på den tid, jeg bruger på arbejde eller andre aktiviteter | ☐ | ☐ |
| B Jeg har nået mindre, end jeg gerne ville | ☐ | ☐ |
| C Jeg har udført mit arbejde eller andre aktiviteter mindre omhyggeligt, end jeg plejer | ☐ | ☐ |

**6.6 Inden for de sidste 4 uger hvor meget har dit fysiske helbred eller følelsesmæssige problemer vanskeliggjort din kontakt med familie, venner, naboer eller andre?** (Sæt kun ét kryds)

| Slet ikke | Lidt | Noget | En hel del | Virkelig meget |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |

**6.7 Hvor stærke fysiske smerter har du haft i de sidste 4 uger?** (Sæt kun ét kryds)

| Ingen smerter | Meget lette smerter | Lette smerter | Middelstærke smerter | Stærke smerter | Meget stærke smerter |
|---|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**6.8 Inden for de sidste 4 uger hvor meget har fysisk smerte vanskeliggjort dit daglige arbejde (både arbejde uden for hjemmet og husarbejde)?** (Sæt kun ét kryds)

| Slet ikke | Lidt | Noget | En hel del | Virkelig meget |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |

**6.9 Disse spørgsmål handler om, hvordan du har haft det i de sidste 4 uger. Hvor stor en del af tiden i de sidste 4 uger:**

| (Sæt kun ét kryds i hver linje) | Hele tiden | Det meste af tiden | En hel del af tiden | Noget af tiden | Lidt af tiden | På intet tidspunkt |
|---|---|---|---|---|---|---|
| A Har du følt dig veloplagt og fuld af liv? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| B Har du været meget nervøs? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| C Har du været så langt nede, at intet kunne muntre dig op? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| D Har du følt dig rolig og afslappet? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| E Har du været fuld af energi? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| F Har du følt dig trist til mode? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| G Har du følt dig udslidt? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| H Har du været glad og tilfreds? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| I Har du følt dig træt? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**6.10** **Inden for de sidste 4 uger, hvor stor en del af tiden har dit fysiske helbred eller følelsesmæssige problemer gjort det vanskeligt at se andre mennesker (f.eks. besøge venner, slægtninge osv.)?**

| Hele tiden | Det meste af tiden | Noget af tiden | Lidt af tiden | På intet tidspunkt |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |

**6.11** **Hvor rigtige eller forkerte er de følgende udsagn for dit vedkommende?**

| (Sæt kun ét kryds i hver linje) | Helt rigtigt | Overvejende rigtigt | Ved ikke | Overvejende forkert | Helt forkert |
|---|---|---|---|---|---|
| A Jeg bliver nok lettere syg end andre | ☐ | ☐ | ☐ | ☐ | ☐ |
| B Jeg er lige så rask som enhver anden, jeg kender | ☐ | ☐ | ☐ | ☐ | ☐ |
| C Jeg forventer, at mit helbred bliver dårligere | ☐ | ☐ | ☐ | ☐ | ☐ |
| D Mit helbred er fremragende | ☐ | ☐ | ☐ | ☐ | ☐ |

## Kontakt med sundhedspersonale

Til slut vil vi bede dig besvare nogle spørgsmål om den eventuelle kontakt med hjemmeplejen, praktiserende læge og palliativt team*.

**7.1** **Hvor ofte kom der hjemmesygeplejersker og hjemmehjælpere hjemme hos din pårørende i de sidste uger?**

| (Sæt kun ét kryds i hver linje) | Hver dag | Flere gange om ugen | Mindre end én gang om ugen | Aldrig | Ikke relevant (var på hospital/på hospice/andet) |
|---|---|---|---|---|---|
| A Hjemmesygeplejersker | ☐ | ☐ | ☐ | ☐ | ☐ |
| B Hjemmehjælpere | ☐ | ☐ | ☐ | ☐ | ☐ |

**7.2** **I hvor høj grad vurderer du, at nedenstående sundhedspersonale ydede den indsats, som din pårørende havde brug for i sine sidste uger?**

| (Sæt kun ét kryds i hver linje) | I høj grad | I nogen grad | I mindre grad | Slet ikke | Ikke relevant (var på hospital/på hospice/andet) |
|---|---|---|---|---|---|
| A Hjemmesygeplejerskerne | ☐ | ☐ | ☐ | ☐ | ☐ |
| B Hjemmehjælperne | ☐ | ☐ | ☐ | ☐ | ☐ |
| C Din pårørendes praktiserende læge | ☐ | ☐ | ☐ | ☐ | ☐ |
| D Palliativt team | ☐ | ☐ | ☐ | ☐ | ☐ |

*Med et "palliativt team" mener vi et team af læger, sygeplejersker, psykologer, socialrådgivere m.fl., som udelukkende tager sig af alvorligt syge patienter og deres pårørende.

**7.3** **I hvor høj grad vurderer du, at nedenstående sundhedspersonale ydede den indsats, som du havde brug for i din pårørendes sidste uger?**

| (Sæt kun ét kryds i hver linje) | I høj grad | I nogen grad | I mindre grad | Slet ikke | Ikke relevant (var på hospital/på hospice/andet) |
|---|---|---|---|---|---|
| A Hjemmesygeplejerskerne | ☐ | ☐ | ☐ | ☐ | ☐ |
| B Hjemmehjælperne | ☐ | ☐ | ☐ | ☐ | ☐ |
| C Din praktiserende læge | ☐ | ☐ | ☐ | ☐ | ☐ |
| D Palliativt team | ☐ | ☐ | ☐ | ☐ | ☐ |

**7.4** **Hvor ofte har nedenstående sundhedspersonale kontaktet dig efter din pårørendes død?**

| (Sæt kun ét kryds i hver linje) | Flere gange | Én gang | Slet ikke | Jeg har selv taget kontakt | Ikke relevant |
|---|---|---|---|---|---|
| A Hjemmesygeplejerskerne | ☐ | ☐ | ☐ | ☐ | ☐ |
| B Din pårørendes praktiserende læge | ☐ | ☐ | ☐ | ☐ | ☐ |
| C Din praktiserende læge | ☐ | ☐ | ☐ | ☐ | ☐ |
| D Palliativt team/hospice | ☐ | ☐ | ☐ | ☐ | ☐ |
| E Hospitalspersonalet | ☐ | ☐ | ☐ | ☐ | ☐ |

**7.5** **I hvor høj grad har du savnet kontakt med nedenstående sundhedspersonale efter din pårørendes død?**

| (Sæt kun ét kryds i hver linje) | I høj grad | I nogen grad | I mindre grad | Slet ikke | Ikke relevant |
|---|---|---|---|---|---|
| A Hjemmesygeplejerskerne | ☐ | ☐ | ☐ | ☐ | ☐ |
| B Din pårørendes praktiserende læge | ☐ | ☐ | ☐ | ☐ | ☐ |
| C Din praktiserende læge | ☐ | ☐ | ☐ | ☐ | ☐ |
| D Palliativt team/hospice | ☐ | ☐ | ☐ | ☐ | ☐ |
| E Hospitalspersonalet | ☐ | ☐ | ☐ | ☐ | ☐ |

## Støtte fra familie og venner

De følgende spørgsmål handler om, hvordan dit forhold til familie og venner er for øjeblikket.

**8.1** **Hvor ofte er du i kontakt med venner, bekendte og familie, som du ikke bor sammen med?** Med kontakt menes der, at I er sammen, taler i telefon sammen, skriver til hinanden m.v. (Sæt kun ét kryds)

| Dagligt eller næsten dagligt | 1 eller 2 gange om ugen | 1 eller 2 gange om måneden | Sjældnere end 1 gang om måneden | Aldrig |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |

**8.2** **Hvordan vil du vurdere den støtte, du får fra dine nærmeste venner og familie?** (Sæt kun ét kryds)

☐ Fremragende

☐ God

☐ Mindre god

☐ Dårlig

**8.3** **Sker det nogensinde, at du er alene, selvom du mest har lyst til at være sammen med andre?** (Sæt kun ét kryds)

☐ Ja, ofte

☐ Ja, engang imellem

☐ Ja, men sjældent

☐ Nej

☐ Ved ikke

**8.4** **Har du nogen at tale med, hvis du har problemer eller brug for støtte?** (Sæt kun ét kryds)

☐ Ja, ofte

☐ Ja, for det meste

☐ Ja, nogle gange

☐ Nej, aldrig eller næsten aldrig

☐ Ved ikke

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## Afslutning

Du er nu færdig med at udfylde spørgeskemaet. Det vil være en stor hjælp, hvis du vil kontrollere, at du ikke er kommet til at springe spørgsmål over i skemaet. Du bedes returnere det udfyldte spørgeskema i den frankerede svarkuvert.
Hvis dine reaktioner efter dødsfaldet giver anledning til bekymring, og du er i tvivl om, om du har brug for hjælp, er det vigtigt, at du søger hjælp, f.eks. hos din praktiserende læge.

**Hvis du ønsker at høre om resultatet af undersøgelsen, når det foreligger om nogle år, send da helst en e-mail til mette.nielsen@alm.au.dk eller du kan angive den her:** (skriv med blokbogstaver)

**Du er meget velkommen til at skrive kommentarer, erfaringer eller tanker i forbindelse med at have mistet en pårørende:**

### Mange tak for din hjælp!

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## Corrections in the published version

| Page | Original text/content | Corrected text/content |
|---|---|---|
| 11 | “In Press for *Clinical Psychology Review*” | “Published in *Clinical Psychology Review* 44 (2016) 75–93” |
| 11 | “Accepted to *Supportive Care in Cancer*” | “Published in *Support Care Cancer* 2016 Feb 18” |
| 16 | “Figure 1” | Deleted |
| 47 | “Figure 3” | “Figure 2.2” |
| 60 | “PCS” | “Physical component score” |
| 60 | “MCS” | “Mental component score” |
| 63 | References under Table 3.4 | Deleted |
| 64 | “PLD” | “Post-loss depressive symptoms” |
| 103-106 | References: 3 (Thomas et al), 7 (Bonanno et al), 10 (Hudson et al), 11 (Stroebe et al) , 12 (Barry et al) and 13 (Archbold et al) | Deleted and remaining references of Chapter 7 corrected |
| 156 | Title page | Title page and abstract (published) |