Bereavement in Healthcare

Implications, Identification and Intervention.

PhD dissertation

Mai-Britt Guldin

Health
Aarhus University
2012
PhD dissertation
Bereavement in Healthcare. Implications, Identification and Intervention.

PhD-student
Mai-Britt Guldin, MSc Psychology, The Research Unit for General Practice, Department of Public Health, Aarhus University, Denmark

Supervisors
Frede Olesen, Professor, GP, DrMedSci, The Research Unit for General Practice, Department of Public Health, Aarhus University, Denmark
Peter Vedsted, Professor, MD, PhD, The Research Unit for General Practice, Research Centre for Cancer Diagnosis in Primary Care, Department of Public Health, Aarhus University, Denmark
Anders Bonde Jensen, Associate Professor, Consultant, Department of Oncology, Aarhus University Hospital
Robert Zachariae, Professor, MDSci, Psycho-Oncological Research Unit, Department of Psychology and Behavioural Sciences, Aarhus University, Denmark.

Assessment committee
Sheila Payne Professor, RN, C. Psychol, Division of Health Research, Lancaster University, UK.
John Sahl Andersen, Associate Professor, GP, Department of Public Health, University of Copenhagen, Denmark.
Morten Høyer, Professor, Consultant, Department of Oncology, Aarhus University Hospital (Chairman)

Financial support
The PhD dissertation was funded by TrygFonden, Dæhnenfeldt Foundation and the Danish Cancer Society.
PREFACE
OUTLINE OF THE THESIS

In Chapter 1, I give an introduction to the domain of research to which this project belongs. The aims of the thesis are presented at the end of chapter 1. In chapter 2, the settings, methods and materials used to fulfil the aims of the thesis are described. Chapter 3 presents the results in short, and chapters 4-7 are the four papers that represent the results. Chapter 8 discusses the methods applied, the validity of the studies and the potential sources of bias which are important in relation to interpreting the results. In Chapter 9, the results of the four papers are discussed, and Chapter 10 presents the conclusions in relation to the aims of the thesis. Chapter 11 brings the results into perspective and suggests implications for healthcare and areas of future research. Chapters 12 and 13 are the English and Danish resumes which are followed by the references and an appendix. The appendix contains the questionnaires and the intervention materials used in Paper four.

This thesis is based on the following four papers:

**Paper 1:** Guldin M, Jensen AB, Zachariae R, Vedsted P.
*Healthcare utilization of bereaved relatives of patients who died from cancer. A national population-based study.* Accepted to Psycho-Oncology.

**Paper 2:** Guldin M, Vedsted P, Zachariae R, Olesen F, Jensen AB.
*Complicated grief and the need for professional support in family caregivers of cancer patients in palliative care. A longitudinal cohort study.* Published in Supportive Care in Cancer.

**Paper 3:** Guldin M, O’Connor M, Sokolowski I, Jensen AB, Vedsted P.
*Identifying bereaved subjects at risk of complicated grief: Predictive value of questionnaire items in a cohort study.* Published in BMC Palliative Care.

**Paper 4:** Guldin M, Vedsted P, Jensen AB, Olesen F, Zachariae R.
*Bereavement Care in General Practice. A cluster randomised controlled Study.*
Provisionally accepted to Family Practice.
Acknowledgements

I dedicate this thesis to the bereaved people who participated in the studies of this thesis while struggling with their loss. I owe a debt of gratitude to you for answering the questionnaires and for sharing your thoughts with me. It is with humble admiration that I follow your process of bereavement and you make me ponder deeply about human emotions and not least the human capacity to cope. I sincerely hope that this thesis will help improve healthcare in the future for those who are facing loss.

I also wish to thank my supervisors. I have thoroughly enjoyed learning the craft of research from you, and I will treasure what I have learned and do my best to live up to the ideals of good research you held ever high during my training years. Thank you Frede Olesen for providing a space for me to do the research I wanted to do most; I can barely find the words to express how much our talks about our healthcare system have meant to me; Anders Bonde Jensen for providing excellent and caring supervision throughout the project, I truly admire your care for the patients; Bobby Zachariae for his high level of expertise and for his steadfast advocacy of the psychologist’s point of view; and Peter Vedsted for his outstanding guidance on methodological issues and inspirational encouragement.

I feel very privileged to have had your attention on this area of research.

A profound thank goes to everyone at the Research Unit for General Practice for making it a great place to work, and to everyone who helped
me in the creation of this PhD project: Hanne Beyer for IT and database management, Kaare Flarup for clever assistance with register data, Eva Højmark for language revisions and for caring involvement, Birthe Brauneiser and Dorthe Toftdal Nielsen for secretarial assistance, Ineta Sokolowski for helpful statistical assistance, Morten Fenger Grøn for eye-opening statistical assistance; Morten Pilegaard for revision of manuscripts, Pia Walfrid for being a very meticulous and interested student worker, and Thomas Mukai for tiffs, eps and mys. I also wish to thank every person with whom I have shared office facilities for their inspiration and for having become dear friends: Trine Brogaard, Rikke Sand Andersen, Thomas Mukai, Margrethe Smidth and Jette Ahrensberg. My profound gratitude goes to Trine Brogaard, Mette Asbjørn Neergaard and Anders Bonde Jensen for companionship in our mutual passion for improving palliative care; and to you Trine: Your generosity is so inspiring to me. Last but not least, I wish to thank the biostatistics group for adopting a psychologist into your great solidarity and for all the fun we have

Last but not least, my deepest gratitude and love goes to my dear and supporting friends who honour me with their loving presence in my life, to my mother and my brothers for their great companionship, and especially my two children, Carl-Emil and Sisse-Mai, for making everyday life filled with wonderful laughter and a deep sense of love and meaning.
### Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>AUC</td>
<td>Area under the curve</td>
</tr>
<tr>
<td>BDI</td>
<td>Beck's Depression Inventory</td>
</tr>
<tr>
<td>CG</td>
<td>Complicated grief</td>
</tr>
<tr>
<td>CI</td>
<td>Confidence interval</td>
</tr>
<tr>
<td>DPM</td>
<td>Dual Process Model of coping with bereavement</td>
</tr>
<tr>
<td>GP</td>
<td>General practitioner</td>
</tr>
<tr>
<td>ICG-R</td>
<td>Inventory of Complicated Grief - Revised</td>
</tr>
<tr>
<td>IR</td>
<td>Incidence rate</td>
</tr>
<tr>
<td>IRR</td>
<td>Incidence rate ratio</td>
</tr>
<tr>
<td>NPV</td>
<td>Negative predictive value</td>
</tr>
<tr>
<td>OR</td>
<td>Odds ratio</td>
</tr>
<tr>
<td>PR</td>
<td>Prevalence rate</td>
</tr>
<tr>
<td>PRR</td>
<td>Prevalence rate ratio</td>
</tr>
<tr>
<td>PPV</td>
<td>Positive predictive value</td>
</tr>
<tr>
<td>PTSD</td>
<td>Post traumatic stress disorder</td>
</tr>
<tr>
<td>RR</td>
<td>Risk ratio (relative risk)</td>
</tr>
<tr>
<td>ROC</td>
<td>Receiver Operating Characteristics curve</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
</tr>
</tbody>
</table>
CONTENTS

PREFACE ................................................................................................................... I

OUTLINE OF THE THESIS ........................................................................................ II

CHAPTER 1 ............................................................................................................... 1

INTRODUCTION ....................................................................................................... 1

THE PROCESS OF BEREAVEMENT ................................................................................. 4

COMPLICATED GRIEF ..................................................................................................... 6

EVIDENCE-BASED INTERVENTIONS IN BEREAVEMENT ....................................................... 8

SETTING THE SCENE ...................................................................................................... 9

1.4.1 Grief reactions as a task of the healthcare system ........................................... 9
1.4.2 Targeted bereavement care ........................................................................... 11
1.4.3 Introduction at a glance ............................................................................. 11
1.4.4 Aim of the thesis ....................................................................................... 12
1.4.5 Aim 1 ......................................................................................................... 13
1.4.6 Aim 2 ......................................................................................................... 13
1.4.7 Aim 3 ......................................................................................................... 13
1.4.8 Aim 4 ......................................................................................................... 13

REFERENCES OF CHAPTER 1 ........................................................................................ 14

CHAPTER 2 .............................................................................................................. 19

SETTINGS, MATERIALS AND METHODS .................................................................. 19

GENERAL INTRODUCTION OF THE STUDIES ................................................................. 20

2.1.1 Summary of papers in this thesis ..................................................................... 21
2.1.2 Data analysis ............................................................................................... 21
2.1.3 Approvals and ethics .................................................................................... 21

PAPER 1 ....................................................................................................................... 22

2.2.1 Setting .......................................................................................................... 22
2.2.2 Design .......................................................................................................... 22
2.2.3 Study population ......................................................................................... 22
2.2.4 Data .............................................................................................................. 23
2.2.5 Analysis ....................................................................................................... 23

PAPER 2 ....................................................................................................................... 24

2.3.1 Setting .......................................................................................................... 24
2.3.2 Design .......................................................................................................... 24
2.3.3 Study population ......................................................................................... 24
2.3.4 Measures .................................................................................................... 25
2.3.5 Analysis ....................................................................................................... 25

PAPER 3 ....................................................................................................................... 26

2.4.1 Setting .......................................................................................................... 26
2.4.2 Design .......................................................................................................... 26
2.4.3 Study population ......................................................................................... 26
2.4.4 Measures .................................................................................................... 27
2.4.5 Analysis ....................................................................................................... 27
Had I known this was about grief, I might have been able to help her. She has contacted me a number of times over the past months...about aches and pains, but she never mentioned she was grieving. It would have explained a lot of her complaints to me.

These are the words of a general practitioner who participated in the study. The quote reflects the fact that it is a challenge to manage bereavement in the healthcare system and that is an inherent part of palliative care. The dominant clinical challenge we are facing is: Who is in need of professional intervention during bereavement? What is the formal task in the healthcare system in managing bereavement?

Over the years, research in the field of bereavement has focused on describing the process of adjustment to loss and how to intervene as a clinician. Research in bereavement and palliative care has only recently begun to elucidate the magnitude of bereavement-related healthcare problems and the effect of bereavement interventions. Still, only little effort has so far been devoted to the systematic identification of bereaved persons in need of treatment, the current use of different intervention methods in bereavement care within the healthcare system, and the best way of organising structured assessment and delivering shared bereavement care, for instance the use of lean principles for the delivery of timely and cost-effective health care [1]. These aspects of bereavement constitute a daily clinical challenge for healthcare professionals in home care, general practice, hospital settings, palliative care and specialist referrals. Hence, because of the current gap in our knowledge of a wide variety of aspects of health services in bereavement care, we are unable to tailor the bereavement health care effort to current needs and to optimise bereavement management, which implies that relatives who lose a loved person often experience unnecessary and prolonged suffering.
This thesis aims at answering some of these questions about the management of bereavement in today’s Danish healthcare system. The thesis focuses on deceased cancer patients’ bereaved relatives and the prevalence and clinical assessment of functional and emotional impairments they suffer because of their loss, as well as their utilisation of healthcare services. Finally, this thesis offers the results a randomized controlled trial testing a bereavement management program in general practice.
THE PROCESS OF BEREAVEMENT

Most people will experience the loss of a significant other and go through the process of bereavement one or several times during their lives. Bereavement is therefore considered an existential process, which for most people tends to be an emotionally demanding and painful experience.

In this thesis bereavement is defined as

*The process of adjustment to a significant loss of a beloved person to whom the bereaved was emotionally attached* [2]

Grief is defined as

*The emotional reaction to the loss of a loved person. It incorporates psychological, cognitive, social, behavioural and physical manifestations.* [2]

A full description of the symptomatology of grief is beyond the scope of this thesis, but grief encompasses reactions such as despair, anxiety, anger, anhedonia, agitation, fatigue, crying, loss of appetite, and sleep disturbances among many other symptoms. [2].

Despite the wide array of symptoms and agonising aspects of adjustment to loss, grief reactions are basically considered normal responses to a critical life event, so grief reactions do not necessarily qualify as an illness or a healthcare problem. Medicalisation of bereavement is a growing concern [3,4], and studies show that many people will adjust to the loss of a significant other within a reasonable period of time and carry on with life without healthcare needs [5]. George Bonanno found that as many as 46% of bereaved people go through a temporary period of emotional responses to the loss and subsequently resume
normal life processes [6,7], and quite a few people even end up feeling enriched by the experience after the first emotionally demanding period of grief has passed [5].

The expression of grief is highly individual and determined by a diversity of factors that are both intrapersonal, interpersonal and related to the circumstances of the death. Margaret Stroebe and Henk Schut have proposed an integrative risk framework for bereavement reactions based on research on risk factors [8]. In their framework, the grief response is shaped by factors such as culture, age, gender, personality, coping processes, the circumstances around the death and especially the relationship to the person who has been lost [8].

Coping with loss has been the subject of much description and theory over the years by for instance Freud, Kübler-Ross, Bowlby, Worden and Parkes [9-13]. For years, the dominant model was the “grief-work hypothesis” based on Freudian theory and the notion that grief was managed by working through the pain [14]. The most recent model, the dual process model (DPM) of coping with bereavement by Stroebe & Schut, has to some extent superseded the grief-work hypothesis, and research based on this new model is emerging [15]. The DPM characterises adaptive coping as a dual process consisting of both emotional adjustment, called loss-oriented coping, and the restoration of life without the deceased person, called restoration-oriented coping [15;16]. The theory rests on the assumption that adjustment to loss is facilitated by a balanced dosage of loss-oriented and restoration-oriented tasks [15;16]. Albeit the present thesis deploys the DPM model, the contributions of other previous theories to the overall understanding of grief/bereavement processes and healthcare professionals’ involvement in these processes should also be acknowledged. Describing and discussing these models is beyond the scope of this thesis, which focuses on bereaved people who develop conditions that need attention from healthcare professionals.
### COMPLICATED GRIEF

A mounting body of research points out that for a small, but significant segment of bereaved relatives, adjustment to loss develops into a persistent and debilitating experience that deviates from the (cultural) norm [2;17;18]. This group of bereaved individuals is facing severe health consequences and elevated risks of morbidity and mortality [19]. Over the years, this impaired grief process has been termed traumatic grief, pathological grief, complicated grief or prolonged grief [2;18]. For the purposes of this thesis, the term complicated grief (CG) is chosen.

CG is characterised as a syndrome with high levels of distress, separation stress, avoidant behaviours, yearning for the deceased, mental health problems, disruptions in work-life and dysfunctions in every-day life [2;18].

Findings generally support the existence of CG as an empirically derived phenomenon with a symptom cluster distinct from the diagnostic criteria of post-traumatic stress syndrome (PTSD) and depression and other mental disorders [17;18;20-24]. CG (and more recently, prolonged grief disorder) has been proposed as a new diagnosis for the Diagnostic and Statistical Manual of Mental Disorders (DSM). CG is not acknowledged as a diagnostic entity at the present time, but several research groups are working to establish its diagnostic criteria and to include its conceptualization into the diagnostic category systems [18;22;25]. This thesis is based on the premise that bereavement-related impairments can be quantified as CG. CG was therefore measured with the Inventory of Complicated Grief – revised version (ICG-R) with a provision of functional impairment for a period of at least six months post loss.
International literature on this subject has shown that the prevalence of CG is around 10-15% in bereaved relatives [18]. In a recent population-based study of risk factors of developing CG, having lost a close relative due to cancer was identified as a risk factor [26]. Hardly any studies have been performed to shed light on the prevalence of CG in Denmark.
Consensus seems to have evolved among bereavement researchers that only bereaved individuals at high risk of CG will benefit from counselling and therapy [27-29]. Research on interventions in bereavement has progressed from the simple belief that support is needed to help any bereaved individual overcome a grief reaction to a more sophisticated understanding that routine intervention cannot be justified [27;29]. Two recent meta-analyses showed that counselling seems to be effective only in bereaved individuals at risk for or suffering from CG [28:30]. Several randomised controlled trials have identified effective treatment methods for this group, but research is still needed to optimise treatment and ensure efficacious interventions towards CG within a comprehensive healthcare system [31-35].
1.4.1 Grief reactions as a task of the healthcare system

The World Health Organisation’s definition of palliative care encompasses taking care of the family caregivers and bereaved relatives of the deceased patient.

**Palliative care:**

- offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;

In this definition, palliative care continues into the bereavement period and frames bereavement support as an inherent part of palliative care. Furthermore, a recent publication from the Danish Board of Health has outlined recommendations for palliative care in Denmark [37]. These recommendations include the period of bereavement and emphasize bereavement support as a central task in palliative care and a task of the public healthcare system in Denmark.

In Denmark, approximately 55,000 people die every year [37]. Cancer is one of the dominant causes of deaths; and in 2010, 15,370 (28.3%) people died from cancer in Denmark [37]. If one were to infer that each dying person leaves at least four relatives, bereavement would affect around 220,000 people every year in Denmark. In approximately one third of these cases, bereavement is due to cancer which, among other things, is characterised by long periods of informal caregiving preceding the loss which, in turn, may influence the bereavement process. Loss to cancer is by far the most common type of loss within
palliative care in Denmark and specialised palliative care is predominantly provided to cancer patients. Yet, no earlier study has focused on this group of bereaved persons in Danish literature. Internationally, bereavement care as a part of palliative care has been put under the microscope, and it has been concluded that research is needed to ensure systematic assessment and targeted support [38;39]. Hence, more research in palliative care is required into the grief reactions that characterise losses after a cancer disease.

In a healthcare system like the Danish, care for the bereaved relatives is left to a wide array of professionals in various settings in hospitals and primary care as well as palliative care. In Denmark, hospital staff are primarily doctors, nurses, and social and healthcare assistants. Specialist palliative care teams are interdisciplinary and consist of doctors, nurses, physiotherapists, psychologists and other healthcare professionals. In primary care, community nurses, general practitioners (GPs), psychologists and psychiatrist are in contact with bereaved individuals. The GP holds a central position as a healthcare coordinator and gatekeeper with regard to medical advice and referral to specialist healthcare services. In a systematic review of bereavement care in general practice, it was concluded that GPs find bereavement care important and satisfying; yet, more training was called for to meet this task [40]. Some studies even point to the fact that healthcare professionals in general and GPs in particular need a knowledge update on bereavement care to enable them to identify patients most at risk [41;42]. According to statistics from the national association of the five regions in Denmark, Danske Regioner, “bereavement due to the death of a loved person” was the primary reason GPs gave for referring patients to psychologists within the public healthcare system in 2006 and 2007 [43]. Other than that, there is no knowledge of the dimensions of bereavement as a clinical syndrome and the extent of healthcare services delivered in response to bereavement. There is need
for a description of the problem and for research than can establish the prevalence of CG and the ensuing need for clinical care.

1.4.2 Targeted bereavement care
A well-functioning healthcare system is ideally organised to ensure early diagnosis and efficient treatment. Bereavement is a par excellence example of a domain where a high demand for healthcare services remains remarkably unexplored and under-researched. Bereavement care can be defined as an integrated clinical discipline in the healthcare system that involves many different healthcare professionals in palliative care, hospital departments as well as primary care. The GP holds a central position in the assessment and planning of targeted and shared care. We currently have no knowledge that can inform healthcare providers on how to coordinate clinical bereavement care, and no systematic assessment of bereavement reactions has been performed to assist proper healthcare planning and to optimise the individual grieving person’s prognosis. Thus, there is a need for health services research that describes the challenges of bereavement care, establishes the prevalence of bereavement-related impairments and explores possible solutions to providing targeted bereavement care within the healthcare system.

1.4.3 Introduction at a glance
- Bereavement is considered an existential process that most people perceive as an emotionally demanding and painful experience. A mounting body of research points to the fact that for a small, but significant segment of bereaved individuals, adjustment to loss develops into a persistent and debilitating experience. These individuals suffer severe health consequences and elevated risks of morbidity and mortality.
Bereavement in Healthcare

• Bereavement is a par excellence example of an area where the demand for healthcare services is high and where coordination and shared care among several professionals in the healthcare system is required. Yet, the challenges of bereavement care in the Danish healthcare system remains poorly researched.

• International studies estimate that 10-15% of bereaved relatives will develop CG during their bereavement process. Estimates among cancer patients’ bereaved relatives are reportedly higher. Knowledge of the prevalence of CG in Denmark is poor.

• Studies show indications of efficacious treatments of CG, but early diagnosis and targeted care is challenged by the absence of appropriate screening and assessment. No systematic assessment methods are currently available to aid informed planning of clinical bereavement care.

• The GP holds the position of healthcare coordinator in the Danish healthcare system, yet training in clinical bereavement care is sparse. Research that explores how GPs may best assume the coordinator’s role the planning and execution of targeted clinical bereavement care is warranted.

1.4.4 Aim of the thesis
The overall aim of this thesis is to address current challenges in bereavement care towards relatives of deceased cancer patients and, in particular, to determine the prevalence of CG in this group, to describe their healthcare utilisation and the assessment of their need for treatment and finally, to test a bereavement management intervention in general practice.

The aim of the thesis is addressed through the following specific aims:
1.4.5 Aim 1
To describe the overall impact of spousal bereavement due to a cancer disease on principal areas of healthcare utilization both before and after the bereavement. This aim is addressed in Paper 1 of the thesis.

1.4.6 Aim 2
To assess the prevalence of CG and depression among bereaved relatives of cancer patients receiving palliative care, and to investigate whether healthcare professionals’ clinical assessment is effective in identifying CG. These aims are addressed in Paper 2 of the thesis.

1.4.7 Aim 3
To investigate the possibility of developing a screening instrument to identify bereaved relatives at risk of developing CG. This aim is addressed in Paper 3 of the thesis.

1.4.8 Aim 4
To test the effects of a program for bereavement care in general practice geared to optimise the identification and treatment of CG. This aim is addressed in Paper 4 of the thesis.
REFERENCES OF CHAPTER 1


CHAPTER 2

SETTINGS, MATERIALS AND METHODS

This chapter portrays and describes the settings, study designs, materials and methods of the individual studies in the thesis.
GENERAL INTRODUCTION OF THE STUDIES

The studies in this thesis are partly descriptive, partly experimental. The thesis consists of four different studies that each has its own data set and its own design:

The first, descriptive part of the thesis is based on a case-control study whose data stem exclusively from registry data, and on a longitudinal cohort study that draws on survey data. This part describes the current provision of bereavement care to the target group (Study 1) and the prevalence of CG within this group (Study 2).

The second, experimental part of the thesis is based partly on a longitudinal cohort study in which questionnaire data are used to establish predictive factors and to inform a screening instrument (Study 3), partly on a randomized controlled study (RCT) that deploys survey and register data to evaluate the effectiveness of a bereavement management program (Study 4).

The setting is the healthcare system in Denmark. Denmark has 5.5 mill inhabitants, and the studies were conducted mainly in the Central Denmark Region, the second largest of the five Danish regions, N=1.2 mill inhabitants. The surveys were conducted in the Central Denmark Region, whereas the epidemiological study as well as the RCT was nation-wide. Table 1 presents an overview of data sources, study designs and outcome measures in the four papers.
2.1.1 Summary of papers in this thesis

Table 1: Summary of papers in the thesis

<table>
<thead>
<tr>
<th>Paper</th>
<th>Source population</th>
<th>Data source</th>
<th>Design</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Bereaved spouses of cancer patients</td>
<td>Register data</td>
<td>Case-control</td>
<td>Healthcare utilisation</td>
</tr>
<tr>
<td>2</td>
<td>Bereaved relatives in palliative care</td>
<td>Survey data</td>
<td>Longitudinal cohort study</td>
<td>CG/depression professional risk assessment</td>
</tr>
<tr>
<td>3</td>
<td>Bereaved relatives in Aarhus County</td>
<td>Register data and survey data</td>
<td>Longitudinal cohort study</td>
<td>Predictive value of survey items to identify CG</td>
</tr>
<tr>
<td>4</td>
<td>GPs and bereaved relatives</td>
<td>Survey and register data</td>
<td>RCT</td>
<td>Assessment, CG, clinical care</td>
</tr>
</tbody>
</table>

For the purpose of overview, the below section will briefly describe the methods used in each of the studies. For a more detailed insight into the materials and methodology of the studies, please see Chapters 3 – 6.

2.1.2 Data analysis

Data analysis conducted using STATA version 10 or 11. Estimates are presented with a 95% confidence interval (CI) where relevant. The statistical significance was set to 0.05 or less.

2.1.3 Approvals and ethics

The studies were approved by the Danish Data Protection Agency and by the regional science ethics committees. Furthermore, the use of register-based data for two of the studies was approved by Statistics Denmark, and the RCT was indexed at Clinicaltrials.gov
Healthcare utilization of bereaved relatives of patients who died from cancer. A national population-based study.

The aim of this study was to describe the utilisation of principal areas of health care among deceased cancer patients’ bereaved relatives.

2.2.1 Setting
This study was set in the Danish healthcare system, and the description was based on register data from Statistics Denmark and the following registries: The Danish Registry of Causes of Death, the Danish National Health Service Register, the National Patient Register, the Psychiatric Central Research Register and the National Prescription Registry [1-6].

2.2.2 Design
A nationwide population-based case-control study was performed to trace healthcare utilisation among bereaved relatives of patients who died from a cancer disease during a period that spanned from two years before their loss to two years after their loss.

2.2.3 Study population
Cases were 6,659 individuals who suffered the loss of a spouse in the year 2005 due to cancer. Cases were identified by linkage to their spouses via their Civil Person Registration number (CPR). Spouses were, in turn, identified as subjects who were registered in the Danish Registry of Causes of Death and Danish Cancer Registry [3] as having died of a cancer disease in 2005. Controls were
66,590 individuals who were age- and gender-matched with cases using incidence density sampling.

2.2.4 Data
Data were collected from a number of comprehensive national health registries to obtain data on services from the GP, referrals to mental health specialist services, admittance to hospitals and consumption of psychotropic medicines.

2.2.5 Analysis
Descriptive statistics were applied to present group means based on the number of services received by cases and controls. The proportion receiving the designated service in each group was calculated together with the prevalence rate ratio.
Complicated grief and need for professional support in family caregivers of cancer patients in palliative care: A longitudinal cohort study.

In this study, we aimed to measure the prevalence of CG and depression among bereaved relatives of deceased cancer patients in palliative care, and to investigate the validity of the clinical assessment of CG and the need for clinical bereavement care.

2.3.1 Setting
The study sample was recruited via the palliative home care team at Aarhus University Hospital in Denmark.

2.3.2 Design
The study was designed as a longitudinal cohort study where CG and depression was measured 2, 6, 13 and 18 months post loss based on self-report survey data. Professional risk assessment was performed 2 months post loss based on an ad-hoc assessment form.

2.3.3 Study population
The study population was professionals of the palliative home care team at Aarhus University Hospital and the 213 patients with whom the team was in contact within the year of the survey (2006) and who died that year. Of these patients 114 had relatives who were subsequently in contact with the team and were therefore eligible for the study. At baseline, 87 bereaved caregivers participated in the study.
2.3.4 Measures

CG was measured with the Inventory of Complicated Grief – Revised version (ICG-R) [7], and depression was measured with Beck’s Depression Inventory II (BDI) [8]. Participants also reported whether they had used any type of bereavement or healthcare service after their loss. Staff at the palliative home care team filled out a clinical bereavement risk assessment form for each of the included participants.

2.3.5 Analysis

The prevalence of CG and depression was calculated based on manualised cut-offs for the scales, and the sensitivity and specificity, positive and negative predictive values of the professional clinical risk assessment were calculated using the levels of CG and depression as a reference.
Identifying bereaved subjects at risk of complicated grief:
Predictive value of questionnaire items in a cohort study.

The aim of this part of the thesis was to explore whether it was possible to develop a model for screening for the risk of developing CG.

2.4.1 Setting
This study drew on two samples of bereaved individuals in the former county of Aarhus. The first sample was identified via the Danish CPR register and consisted of all 65-80-year-old persons who had lost a spouse during the year of 2006 [9]. The second sample was recruited via the palliative home care team at Aarhus University Hospital.

2.4.2 Design
The study was designed as a longitudinal cohort study with measurement of CG and depression at 2, 6, 13 and 18 months post loss based on self-report survey data collected through mailed questionnaires. The responses obtained at baseline and at the six-month follow-up were used for the analyses in this study.

2.4.3 Study population.
A total of 952 bereaved relatives were eligible for inclusion; 838 were sampled through the CPR register and 114 via the palliative home care team. In both samples, a total of 416 (46%) participated in the study at baseline. Due to non-response, only 276 bereaved relatives were still in the study at the six-month follow-up and their responses were analysed for this study. The two population
samples were both used in other studies [9], and the cohort sampled via the palliative home care team was also used in Study 2 of this thesis.

2.4.4 Measures
Data collection was based on self-reported questionnaires containing a number of standardized scales, for instance the ICG-R (7) and the BDI [8] as well as a number of ad-hoc single item questions on distress and the meaning in life.

2.4.5 Analysis
Receiver-operating characteristics (ROC) curves were drawn for all scales and items at baseline with the scores on the ICG-R at six months as a golden standard to analyse the discriminating capacity of questionnaire items [10]. A multivariate model of sensitivity and specificity was used to select the combination of scales and items that best predicted CG.
2.5.1 Setting
This study took place among GPs and their bereaved patients in Denmark in general and in the Central Region Denmark in particular.

2.5.2 Design
This study was designed as a cluster-randomised controlled trial with two parallel groups of bereaved relatives of deceased cancer patients and their GPs. Bereaved participants answered questionnaires at 2, 6, and 13 months post loss, and GPs gave a clinical grief assessment at 13 months post loss. Data on contacts to the GPs were retrieved from the Danish National Health Service Registry [2].

2.5.3 Study population.
Newly bereaved relatives were included according to inclusion criteria communicated to the inclusion sites at hospital departments at Aarhus University Hospital, three palliative care teams in the Central Denmark Region, two hospices in the vicinity of Aarhus, and Bispebjerg palliative care unit in Copenhagen. Of the 745 relatives assessed for eligibility, 402 (54%) were allocated for randomization and 321 stayed in the study until 13 months post loss.
2.5.4 Intervention
The intervention was designed as a complex intervention with several elements inspired by earlier studies on the subject [11-14]): a pilot-tested information pamphlet to patients and GPs with updated information on CG [15-18], the DPM theory of adaptive coping [19], as well as information about the results of the patient’s baseline risk assessment [20]. GPs also received suggestions on how to provide support for the patient, while patients were encouraged to contact their GP if they worried about handling their grief reaction.

2.5.5 Measures
Assessment was based on the results of the ICG-R and the BDI evaluations as well as GP’s clinical grief assessment and registry-based data on contacts to the GP.

2.5.6 Analysis
The following hypotheses were tested in the analysis: the intervention a) facilitated identification of CG, b) optimised use of treatment options available to patients with CG, c) alleviated grief symptoms more efficiently than usual care, and d) reduced contact rates to the GP among intervention subjects. a) The prevalences of CG and depression were calculated based on mean scores and also on manualised cut-offs for the respective scales. Sensitivity and specificity, positive and negative predictive values of the clinical grief assessment by the GPs were calculated using the levels of CG as a reference. b) The risk and risk differences of receiving designated treatment options were analysed based on the CG symptom level at six months to test whether the presence of CG at baseline gave rise to different treatments in the groups. c) The differences in the sum scores of the ICG-R scale between the groups were tested with a Mann-Whitney rank-sum test. d) GP contact rates and the rate ratios between groups
were analysed using a negative binomial regression to adjust for individual differences in contact rates [21].
REFERENCES OF CHAPTER 2


Ref Type: Pamphlet


CHAPTER 3

RESULTS

This chapter offers a brief presentation of the main results of the studies in relation to the aims of the present thesis (chapter 1). A detailed and tabulated presentation of the results is given in Chapters 4-7 where each paper is presented.
The study found that the bereaved spouse’s use of healthcare services, including the spouse’s consumption of psychotropic medicine, began to rise months before the loss and peaked around the time of the loss where consumption of out-of-hours services, in particular, grew markedly (20%). The proportion of relatives referred to psychologists was much higher the year after the loss than the year before the loss (prevalence rate ratio (PRR) = 14.58, 95% confidence interval (CI)=12.48-17.03), and the second year after the loss saw a notable rise in referral to psychiatric care (28%). The probability of being admitted to a somatic hospital rose by 10% whereas admittance to a psychiatric hospital more than doubled (PRR=2.15, 95%CI=1.77-2.60). Lastly, the use of psychotropic medicine was markedly increased around the time of the loss and during the first year after the loss (sedatives: PRR=1.89, 95%CI=1.80-1.98; anxiolytics: PRR=2.16, 95%CI=2.06-2.27; antidepressants: PRR=1.63, 95%CI=1.54-1.72). The bereaved spouses’ healthcare utilisation remained elevated throughout the first year after their loss.
PREVALENCE OF BEREAVEMENT-RELATED IMPAIRMENTS

The prevalence of mental health problems experienced by bereaved relatives was explored in two studies, Studies 2 and 4. Study 2 found a prevalence of symptoms suggestive of CG of 28% and a prevalence of symptoms suggestive of moderate to severe depression of 13% among bereaved relatives at 13 months post loss. In 11% of the bereaved individuals, the symptoms of moderate to severe depression persisted or worsened from baseline to 18 months post loss. In Study 4 which focused on the development of grief symptomatology, the prevalence of symptoms suggestive of CG was 15-18% and the prevalence of symptoms indicating moderate to severe depression was 9-11% in the study population 13 months post loss.
Clinical assessment of bereavement-related impairments was performed by healthcare professionals in Study 2 and Study 4. Healthcare professionals undertook the clinical assessment of the bereavement-related impairments presented by the bereaved relatives in Studies 2 and 4 using the ICG-R as a reference for CG and the BDI as a reference for depression, but found 50% or fewer of the designated disorders. In Study 2, the clinical assessment was performed by specialised palliative care staff who found a sensitivity for CG of 27.3% (95%CI = 6.02-61.0) and for depression of 54.5% (95%CI = 23.4-83.3) and a specificity for CG of 62.7% (95%CI = 49.1-75.0) and for depression of 86.4% (95%CI = 75.0-94.0). The positive predictive value (PPV) and the negative predictive value (NPV) for CG were 21.4% (95%CI = 6.02-61.0) and 86.4% (95%CI = 75.0-94.0), respectively, and for depression 27.3% (95%CI = 6.02-61.0) and 86.4% (95%CI = 75.0-94.0), respectively.

In Study 4, the clinical assessment was performed by the GP of the bereaved relative, and the sensitivity of the clinical assessment of CG in the intervention group was 42.9% (95%CI: 21.8-66.0) and the specificity 73.8% (95%CI: 61.5-84.0), the PPV was 34.6% (95%CI: 17.2-55.7), and the NPV was 80.0% (95%CI: 67.7-89.2). In the control group, the sensitivity was 40.0% (95%CI: 19.1-63.9), the specificity was 83.7% (95%CI: 70.3-92.7), the PPV 50.0% (95%CI: 24.7-75.3) and the NPV 77.4% (95%CI: 63.8-87.7).

Study 3 proposed a model for risk screening using the ICG-R as a reference. The risk screening consisted of BDI, which was the scale with the highest area under the curve (AUC) (0.83) and a negative answer on the single-item question “Even while my relative was dying, I felt a sense of purpose in my life”, which yielded a sensitivity of 79.6% (95% CI = 66.5 - 89.4) and a specificity of 75.2% (95%CI =
69.0 - 80.8). The PPV was 43.9 % (95%CI = 33.9 - 54.3) and the NPV 93.8% (95%CI =89.2 - 96.9).
EFFECT OF A RANDOMISED CONTROLLED TRIAL OF BEREAVEMENT CARE IN GENERAL PRACTICE

In this cluster-randomized controlled study, we found indication of an effect of the intervention compared with usual care. In the intervention group, symptoms suggestive of CG decreased from 38 (22%) at six months post loss to 24 (15%) at 13 months post loss; in the intervention group, they fell from 29 (19%) at six months to 25 (18%) at 13 months post loss (p=0.07; Mann-Whitney test).

GPs in the intervention group favoured the following treatment options for patients with CG: to give information (RR= 1.6 (95%CI = 0.8-3.3) in the intervention group; 0.8 (95%CI = 0.3-2.2) in the control group), supportive care (RR=1.7 (95%CI = 1.0-2.8) in the intervention group; 1.4 (95%CI = 0.8-2.5) in the control group), and referral to a mental health practitioner (RR= 2.2 (95%CI = 1.1-4.3) in the intervention group; 2.2 (95%CI = 1.0-5.1) in the control group).

GPs in the control group favoured prescription of psychotropic medicine (RR= 4.1 (95%CI = 1.7-10.1) in the control group; 2.3 (95%CI = 1.0-5.0) in the intervention group.)
CHAPTER 8

DISCUSSION OF METHODOLOGY OF THE STUDIES

This chapter discusses the methods of the studies in the present thesis and offers an overview of the study designs. The strengths and weaknesses of the individual studies will be discussed in relation to design, data collection and analyses; and the individual studies’ validity will be discussed in terms of selection bias, information bias, confounding and generalisability.
The designs included two longitudinal cohort studies, a case-control study and a cluster-randomised clinical trial. Bereavement research has traditionally deployed qualitative research designs, but we favoured a quantitative approach for several reasons. First, a quantitative approach would afford us with a more comprehensive description of the phenomenon in question. It also allowed us to present an overview of the healthcare utilisation of deceased cancer patients’ bereaved spouses in a nationwide case-control study and to measure the prevalence of CG in two different cohorts of cancer patients’ bereaved relatives as stated in the first and second aim in Chapter 1. Second, only a quantitative design would allow exploration of risk factors and predictive questionnaire items as stated in the third aim, Chapter 1. Third, and not least, a quantitative approach is well-suited for testing specific hypotheses both in relation to theories, interventions and new treatments as needed to reach the fourth aim.

8.1.1 Case-control study
To satisfy the first research aim, we conducted a register-based case-control study to determine if going through a bereavement process was associated with overall increased healthcare utilisation. The case-control study measures incidence rates, but does it so much more efficiently than for instance a cohort study because of the way in which the cases are sampled [1]. We sampled bereaved subjects, the exposed cohort, and matched them on age and gender with a comparable cohort of unexposed subjects. The incidence rate was determined for the individuals in the two cohorts, and incidence rate ratios were calculated to compare cases and controls. The main advantage of this type of observational study lies in its feasibility and time-efficiency (as opposed to the cohort studies in the thesis) because data can be collected at one time [1].
Another advantage lies in its statistical power, which is high because it is possible to sample many cases quickly; in our study, the study population was nation-wide. This provides the estimates with high precision. On the other hand, the data level can be quite coarse, and it delivers no information at the level of the individual; nor does it allow us to outline timelines in the bereavement process or identify mediators of outcome. A crucial point in the design of a case-control study is the sampling of a control group and how groups are matched. We used incidence density sampling [1] which allowed matching based on age and gender so that we could compare incidence rates and incidence rate ratios between the exposed and unexposed subjects assuming that we had taken the most important confounders into account in the matching procedure.

8.1.2 Longitudinal cohort study
A longitudinal cohort design was chosen to establish the incidence/occurrence of grief symptoms within the cohort of bereaved relatives and to determine the incidence rates of CG and identify any possible predictive variables. The occurrence and frequency of illness is a core issue in epidemiology where the cohort study is a classic design in epidemiological research [1]. The prospective longitudinal design is the strongest possible design for tracing changes over time and was therefore an obvious choice for the investigation of the dynamics of the grief process. Prospective cohort studies are considered reliable in observational epidemiology as recall biases are minimized compared with a retrospective design; but prospective cohort studies require long time to collect useful data and they can therefore be sensitive to attrition [1]. Both recruitment and attrition were a challenge in our designs, and selection bias is therefore thoroughly considered and discussed later in this Chapter. Our follow-up was 18 months at the longest, which must be considered a very short period for a grief process. The choice of an 18-month period was rooted partly in considerations of feasibility; yet we do acknowledge that a longer study period
would have allowed for a more detailed analysis of changes in symptomatology during the bereavement process.

8.1.3 Randomised controlled trial

The randomised clinical trial is one of the most reliable methods for acquiring valid information about the clinical effect of a specific intervention [2] and it was therefore used to explore the fourth research aim. Cluster randomisation was deemed the best design in this case because it takes into account that the participating GPs could have more than one patient in the study. More importantly, many GPs work together in their practices, so the adoption of the cluster randomisation principle minimised contamination of the control group. The randomisation was successful: two groups were formed that were equal in terms of age, gender and educational level. The cluster design invites confounding in two ways. First, some GPs had several participants in the study, while others only had one; second, the intervention served, among others, an educational purpose and we could not determine either the extent or the permanency of its effect. This was taken into account in the analyses by adjusting the variance to minimise the effect of an uneven distribution of confounders [1]. The randomisation unfortunately meant that intervention group and control group GP contact rates differed both before bereavement and during the intervention. This difference was only present in the contact rates in the two study groups and was not seen as a difference in the proportion of patients seeking contact in the groups, and we estimated that it was not a flaw in the randomisation. We analysed contact rates both before and after the loss to adjust for this imbalance in the final analyses of the study. Blinding is not possible in a clinical trial that involves educational information. The randomisation status could therefore not be blinded to GPs in the intervention group as it was a strategic component of the intervention to disclose this information and for the GPs to receive a knowledge update. This might have
influenced the GPs’ choice of treatment, i.e. the so-called Hawthorne effect, in so far as subjects may modify their behaviour because they know that they are being studied [1]. On the other hand, the GPs were not informed about the measures of the study, and they did not know the contents of the items in the questionnaires filled in by the patients.
8.2.1 Patient questionnaires

CG is an empirically constructed phenomenon [3] and normal versus pathological symptoms of grief were assessed from self-report questionnaires by the patients [3]. All patient questionnaires were constructed on the basis of two validated rating scales: the BDI [4] and the ICG-R [5]. Both scales are commonly applied in bereavement research and used to assess the level of grief symptoms. The BDI is widely known and validated in international as well as Danish populations. The quantification of CG is empirically less firmly grounded and we favoured the ICG-R over other potentially applicable measuring scales [3] because it specifically measures symptoms of maladaptive adjustment to loss and because it is the most widely used instrument which therefore affords us with the possibility of comparing our results with those of other studies [3;5;6]. Moreover, the scale had already been translated into Danish and had been employed in another Danish study [7]. Unfortunately, the ICG-R had not been validated in a Danish population, and cut-off values for the scale were defined according to the recommendations of the authors of the original scale and were in conformity with a previous Danish study [5;7]. This evidently challenged our interpretation of the cut-offs for the ICG-R, especially in Study 2 where the symptom level of CG among the bereaved relatives was very high. This thesis aims neither to test the psychometric properties of the ICG-R, nor to validate the scale in a Danish population, but assessment with a validated scale or even structured clinical interviews with trained professionals would undoubtedly have given a more reliable and valid assessment process.
8.2.2 GP questionnaire

In the RCT, a questionnaire was devised to obtain knowledge of the GPs’ assessment and clinical care strategy. In Study 2, a short questionnaire was designed to obtain the clinical assessment of healthcare professionals in palliative care. No existing validated scales were available for these purposes, but the design and the items of the ad-hoc questionnaires were informed by previous GP questionnaires designed at our research unit. The questionnaires were pilot-tested to ensure that they were comprehensible and applicable among the healthcare professionals and in general practice. The assessments and other information obtained by means of these questionnaires are therefore subject to some uncertainty and there is a risk of a systematic error. This is further discussed in Chapter 7 of this thesis.

8.2.3 Register data

Denmark is well-known for its valid and extensive registration of data describing the socio-economic status, the health status and the health care utilization of its citizens. Studies 1, 3 and 4 of this thesis draw on these data, which were retrieved from a range of national health registries. In Study 1, data were derived from The Danish Registry of Causes of Death, the Danish National Health Service Register, the National Patient Register, the Psychiatric Central Research Register and the National Prescription Registry [8]. We decided to calculate group means and proportions of persons who had utilised a wide range of healthcare services: for instance general practice, referral to mental health practitioners, admittance to hospitals and the use of psychotropic drugs. Other variables could have been included, for instance contacts to psychiatric outpatient clinics or emergency wards. The variables were chosen to reflect overall patterns in healthcare utilisation, and the utilisation of specialist services was not scrutinised in this study. The accuracy and completeness of the register-based data is generally considered to be high as the data are being continuously
used and updated by administrative systems in the Danish healthcare system [8]. Furthermore, in some of the registries, data are used for reimbursements or they are required by law which also ensures a high level of precision in data recording. Inaccuracies were therefore considered to be minor, except for referrals to psychologists which often take place under the auspices of private health insurances, and data on referrals to psychologists are therefore not complete. In the future, new methods must be applied to account for the number of sessions with a psychologist in relation to bereavement. Study 3 used register data to identify persons who experienced spousal loss, and Study 4 used data from the Danish National Health Service Register [9] to determine the nature and number of contacts to GPs.

8.2.4 The intervention
The intervention was complex and had several components: a pamphlet with detailed, updated, evidence-based knowledge of bereavement and CG [6;10-12]; a risk assessment of the patient; and suggestions for supporting the patient according to the theory of the DPM [13]. Drawing on the conclusions from previous studies on bereavement in primary care, we decided to construct an intervention that informed the GPs that their patients were grieving and featured an educational component to update their knowledge of bereavement and to improve their assessment and support skills [14-16]. A literature search identified the DPM as a theoretically sound and clinically effective method for enhancing the GPs’ grief assessment and support skills. A recent study concluded that clinicians’ knowledge of theoretical models of grief seemed to be outdated, and many healthcare professionals might not know the DPM model, which backed our decision to include information on this model in the intervention [17]. A drawback of this design is that it reduces our opportunities to undertake a more detailed evaluation of the effectiveness of the individual components in the intervention.
8.2.5 Statistical precision

Due to the very different sample sizes of the studies in this thesis, the statistical precision of each study varied with its design and study population.

Sample sizes were determined to avoid unnecessarily large samples, which are costly, time-consuming and impose a needless burden on the study population; yet, the sample size has to be sufficiently large to accommodate the variance of outcome and the risk of random errors or type II error [1]. In Study 1, the register-based case-control study, the study population was population-based and nationwide. Its statistical precision was very high, and the risk of random errors very small.

In the cohort studies, Studies 2 and 3, statistical precision was adequate for descriptive statistics and the calculation of predictive values, but the possibilities of multivariate analyses were limited. In Study 3, we performed receiver-operating characteristics (ROC) analysis to determine the predictive values of the questionnaire items. It would have added precision to the estimates had the sample been larger, and there were some notable limitations in the proposed screening model.

In the randomised controlled study, Study 4, descriptive and bivariate analyses were undertaken to identify differences between the intervention group and the control group. The sample size was calculated on the basis of an estimate that 20% of deceased cancer patients’ bereaved relatives would experience CG and that 50% of psychiatric patients are diagnosed in general practice [18]. We set the minimal relevant difference to 10% with alpha=5% and beta=80%; and considering the design effects of cluster randomisation and dropout rates, the total number needed was set to 600 patients. A little more than 700 relatives were eligible for the study during the study period, but only 402 answered the patient questionnaire and could be randomised. The sample size was therefore inadequate for a conclusive interpretation of the results even if the findings did
indicate that the intervention had an effect. Furthermore, the sample size was also too small to do sub-group stratification and perform multivariate analyses, but risks and risk ratios between the intervention and the control groups were performed.

8.2.6 Selection bias

Selection bias is a systematic source of error in a study and might arise if data stem from procedures used to select subjects and from factors that influence study participation [1]. In bereavement studies, the risk of selection bias is generally high due to high attrition rates [19], which was also the case in the cohort studies of this thesis. The case-control study was subject to a restricted selection because we sampled deceased cancer patients’ spouses, whereas the study population in the other studies included bereaved persons with different relations to the deceased. This was done in order to define a relationship with the deceased that was possible to track within registers, and we estimate that this restriction is a study limitation more than a selection bias.

Concerns about selection bias in the studies of this thesis arise mainly from non-participation in Studies 2, 3 and 4. Response rates in the cohort studies (Studies 2 and 3) were 77% and 46%, respectively. In the literature, low acceptance rates in bereavement studies are not unusual. For example, the acceptance rates were below 50% in half of the studies included in a review of participation rates in bereavement studies [19]. The review also concluded that participation rates are usually higher when the participants are included by medical personnel [19]. Coincidently, the difference between Studies 2 and 3 lies in the contact method; in Study 3 where the response rate was lower, most of the sample was recruited on the basis of register information on dead spouses. No significant differences between non-respondents and respondents were seen in Study 2, but a larger proportion of women participated, and this invited methodological considerations about the study population’s representativeness. In Study 3,
analyses showed that respondents differed from non-respondents in terms of age and gender, which led to the conclusion that the results might underestimate the risk for women and older people, which should be taken into account when applying the screening tool.

Also, Study 4 suffered the risk of selection bias. Participants were recruited at hospital wards, hospices and by palliative care teams, which increased the risk of self-selection and the risk of unsystematic inclusion. Analyses showed that men were underrepresented, which was also the case for relatives with a relation to the deceased person other than spouse or child. Hence, caution is advised in any application of the results to groups other than those included in the study. In regard to response rates among GPs, the majority of the GPs returned a questionnaire (99%), but only 70% reported having had contact with the patients related to the bereavement process. One third of the GPs thus did not communicate with their patient about the grief response or were not aware that the patient was grieving. For some of these GPs, this might reflect their approach to bereavement and hence reflect self-selection. If this is the case, the effects of the intervention might be overestimated for this group of GPs. In conclusion, three of the studies come with some risk of selection bias, which was taken it into consideration when interpreting their results.

8.2.7 Information bias

Information bias is another type of systematic error that may arise in case the information collected about or from the study subjects is erroneous or misclassified [1]. The use of register data in this thesis minimises the risk of information bias. Yet, misclassification happens primarily when the variable is measured on a categorical scale and the error causes a person to be placed in an incorrect category [1]. In the cohort studies and the randomised clinical trial, the dominant type of information bias is the risk of misclassification of CG. The construct of CG is not formally authorized or merited, and while some aspects
of the use of CG as a diagnostic entity remain unresolved, the symptoms of CG have been shown to be distinct from bereavement-related depression and anxiety [6;10;20]. Still, this issue raises the question of the construct validity of our outcome measure [21]. The ambition of this thesis is not to clarify the construct of CG or even to validate measures of CG. This thesis accepts an operational definition of CG as described by a group of bereavement researchers lead by Professor Holly Prigerson [5;6]. We therefore deployed the ICG-R [5] as an assessment instrument and are satisfied that it has been accepted in the literature as a standardised instrument for determining the prevalence of bereavement-related distress. The ICG-R has previously been shown to enjoy a high internal consistency (Cronbach’s $\alpha > 0.94$) and a 6-months test-retest reliability of 0.80 [5]. The choice of the ICG-R as a fitting measure was first of all pragmatic, as there was already a Danish version of the instrument [7]; secondly, it was derived from research on persons most of whom died from cancer [3], which matched our needs. Since the planning of the studies in this thesis, the scale has been further developed into the instrument the PG-13 [6], which is a shorter version of the scale and whose items reflect the latest research on CG. This scale should be considered for measuring grief symptoms in the future.

### 8.2.8 Confounding

A confounder is a factor which is associated with both the exposure and the outcome, and the experimental design of the study or the statistical analysis therefore aims to control or account for this factor [1]. Confounding is primarily of importance in the non-experimental part of this thesis as the randomisation of the clinical trial acts as a means of confounder control. Confounding is a central issue in epidemiologic study designs as it is a challenge to distinguish between effects of the exposure and factors that are correlated with the outcome [1]. In the case-control study, we attempted to control for major potentially confounding variables such as age and gender through the matching procedure.
in the study design. Yet, the single status of the bereaved relatives may be an important factor that might constitute a confounder in the outcome of healthcare utilisation post loss. In the study, bereavement is associated with the duration of hospital admittance and the use of antidepressants; yet, it was not established whether this was a result of the bereaved relative’s loss or the relative’s status as a single. To control for this potential confounder, we would have to match our cases with persons of single status to compare their healthcare utilisation.

In the cohort studies, it was attempted to account for potential confounders such as age, gender, educational level and relation to the deceased by describing the presence of these factors and by discussing to which extent they might influence the results.

8.2.9 Generalisability

The question of generalisability considers whether results are valid in other populations [1]. In this thesis the issue of generalisability is relevant in the context of the findings of the cohort studies, Studies 2 and 3, and whether they could be extrapolated to all relatives of deceased cancer patients receiving palliative care, even internationally. In the case-control study, Study 1, the question would be whether the healthcare utilisation patterns could apply to bereaved relatives of cancer patients outside the Danish healthcare system, and in the case of the randomised controlled study, Study 4, whether the findings would apply to GPs and their bereaved patients in other countries. The generalisability of the individual studies that constitute the present thesis is discussed in Chapters 4-7. A number of issues should be raised when discussing whether the results of the present thesis apply to a wider population. In the cohort studies, the study population was recruited from the Aarhus County of the Central Denmark Region. The organisation of healthcare is considered to be quite homogenous across the country, and the Central
Denmark Region consists of both urban and rural areas and can be considered representative of the Danish population, wherefore the findings may be extrapolated to a national level. The case control study and the randomised controlled trial were already nationwide. Still, any international generalisation requires thorough consideration of differences in healthcare systems and culture in general and health behaviours in particular. The Danish healthcare system is characterised by being tax-financed, medical care is free of charge, and the GP acts as a gatekeeper and coordinator of medical care. We estimate that generalisability is possible to healthcare systems organised in a similar way.
ETHICAL CONSIDERATIONS

Careful consideration was given to the ethical dilemmas of this study. The studies were planned based on internationally recognized procedures for scientific, quantitative studies. It was paramount that no participant in any of the studies was placed in a position of getting less than usual care during bereavement, and that the intervention in the randomised controlled trial exposed participants to no risks. At the end of the questionnaires, patients and GPs were given the opportunity to write in their own words if aspects of bereavement they considered important had not been mentioned. Some patients wrote that participation was distressing, but far more patients wrote that participation felt meaningful and important, and the feeling of helping others in the same situation with their responses was essential. All the studies in this thesis were subject to scrutiny by the Scientific Ethics Committee in Central Denmark Region as well as General Practitioners Organisation (PLO) and the Danish Society of General Practice’s Committee for Clinical Trials in General Practice (DSAM’s Udvalg for Multipraksisundersøgelser).
REFERENCES CHAPTER 8


CHAPTER 9

DISCUSSION OF MAIN RESULTS

This Chapter discusses the results of the studies in the thesis in light of their aims and any previous research and existing literature on the subject. The discussion focuses on health services research questions relevant to the management of bereavement within the context of the healthcare system.
The first aim was to map bereaved spouses’ healthcare utilisation. Inspired by a few previous studies, we hypothesised that bereavement would be associated with a substantial rise in overall healthcare utilisation, although prior studies had only investigated healthcare utilisation in relation to a single designated healthcare service like for instance consultations in general practice or a particular bereavement service [1-4]. Study 1 revealed a distinct overall increase in healthcare utilisation among bereaved relatives with a characteristic spike-like pattern around the time of the loss for several of the healthcare services scrutinised. The increase in GP-provided services began months before the loss and peaked at the time of the loss, where a notable rise (20%) in out-of-hours services consumption was observed; referrals to psychologists rose immediately around the time of the loss; referrals to psychiatric care saw a notable rise the second year after the loss (28%); the length of stays at hospitals doubled right after the loss; and, lastly, the use of psychotropic medicine rose markedly around the time of the loss. The rise in healthcare utilisation was evident even before the loss and for months or in some cases years after the loss. These findings are consistent with previous studies on this topic [1-4]. However, to our knowledge, the present study is the first that offers a comprehensive overview of healthcare utilisation in a nationwide sample and that encompassed healthcare utilisation both before the loss and years after the loss. In some of the previous studies mentioned, the investigation of healthcare utilisation was based on self-report questionnaires, which was also the approach we used in Study 2 of the present thesis. The self-reported use of certain types of bereavement services offered by GPs, psychologists or chaplains was established. Among the study population in Study 2, 48% of the participants had
used some type of bereavement service two months after the loss. This finding was comparable to that reported in other studies with a similar study population [5;6]. Like comparable studies, our study showed that bereavement services were not necessarily offered to the persons with the most severe grief reactions, nor were services offered in a targeted manner or on the basis of a standardised risk assessment [5;6].

These results provide new knowledge of the patterns of healthcare utilisation associated with bereavement, and they establish a sound basis for further analysis that may be instrumental in uncovering potential risk factors and establishing the relationship between long-term physical and psychological dysfunctioning and healthcare needs during the bereavement process.
PREVALENCE OF BEREAVEMENT-RELATED IMPAIRMENTS

To better understand the mechanisms behind the increased use of healthcare services and to examine who suffers from bereavement-related impairments, we examined the prevalence of CG and depression post loss. The prevalence of mental health problems experienced by bereaved relatives was explored in Studies 2 and 4. In accordance with previous studies in this field, CG and depression were chosen as a measure of these impairments [5;7-13]. In Study 2, we found that the prevalence of symptoms suggestive of CG was 28% and the prevalence of symptoms suggestive of moderate to severe depression was 13% at 13 months post loss. Study 4 monitored the development of symptomatology: at 13 months post loss, the prevalence of symptoms suggestive of CG was around 15-18% and the prevalence of symptoms indicating moderate to severe depression was around 9-11%. This difference in prevalence may be ascribed to differences in the study population, as the participants in Study 2 were bereaved relatives of deceased cancer patients who had received palliative care. In Denmark, as in most other countries, only the segment of patients and relatives with the most severe symptoms and the highest need of support get access to specialised palliative care, which may influence the level of bereavement-related distress post loss and explain the high rates of symptoms indicating CG. The prevalence of CG in Study 2 was slightly higher than that reported for some of the comparable study groups (12-30%) [5;7-10;14]. This difference may be attributable to the lack of validation of the scale of the ICG-R instrument in Danish, which should be taken into consideration when comparing our results with those obtained in international samples.

The present studies are among the first to establish the prevalence of CG in a Danish population, and they indicate that a substantial number of deceased
cancer patients’ relatives have CG reactions. The incidence of CG was slightly higher in our studies than the 9-12% incidence rates reported in international studies [14]; and for bereaved relatives of cancer patients in palliative care, the CG incidence rates may be even higher. More prevalence studies are needed to confirm findings, and there is a need for a standardised and validated grief reaction inventory to standardise the assessment.
PROFESSIONAL ASSESSMENT OF BEREAVEMENT-RELATED IMPAIRMENTS

Having established the prevalence of CG and depression in relation to bereavement, we wanted to explore to which extent bereavement-related impairments are actually detected. Clinical assessment of bereavement-related impairments was performed by professionals in Study 2 and Study 4. In both studies, the professional assessment lacked precision, and only 50% or fewer of the designated disorders were identified as needing clinical attention. In Study 2, the PPV and NPV were 21.4% (95%CI = 8.3-41.0) and 88.1% (95%CI = 74.4-96.0), whereas in Study 4 the PPV and NPV were as high as 50.0% (95%CI = 24.7-75.3) and 77.4 (95%CI = 63.8-87.7). This difference in precision may be rooted in some of the differences between Study 2 and Study 4: a) In Study 4, the professionals were GPs, whereas in Study 2 they were palliative care staff (nurses and doctors). It is possible that GPs are more precise in their clinical assessment because they have known the bereaved relatives for a longer period and have a more thorough knowledge of the bereaved relative. b) The GP questionnaire may have been more comprehensible than the assessment form used in Study 2 owing to its prior pilot-testing.

A number of studies have described bereavement risk assessment in palliative care [6;15], but no other study was found that compared professional risk assessment with CG symptom level. Yet, a previous study by Wiles and colleagues, which examined referral for bereavement counselling in primary care, pointed to the fact that GPs do not systematically assess the risk of complicated grief reactions and certain patient groups’ specific needs may therefore be overlooked [16].
In Study 3, we tested a clinical tool that could be deployed to determine the risk of CG in general practice and palliative care. Using the ICG-R as a reference and performing a ROC curve analysis of the predictive value of questionnaire scales and single items, we were able to identify a model that could be used to screen for the risk of developing CG. The model proposed was based on a score > 19 on the depression scale, the BDI, and a negative answer on the item “Even while my relative was dying, I felt a sense of purpose in my life”. Although studies on risk factors in bereavement are legion [17;18], no previous study has investigated the predictive value of a short screening model. A standardised screening tool may, indeed, be crucial to a) early identification of bereaved individuals susceptible to developing complications during a period of grief, b) clinical decision-making, and c) prevention of prolonged suffering. Still, this screening tool needs to be validated in a clinical setting and in other populations of bereaved persons.

Our studies show that professional assessment of grief symptoms lack in precision if measured against the symptoms of CG. In the particular population of deceased cancer patients’ bereaved relatives, depressive symptoms immediately after the loss predicted CG. We found no other study testing the precision of such clinical assessment, but another study found that assessment procedures in general practice regarding bereavement were lacking. The validity of the clinical assessment by professionals is important to the assessment of the grief reaction and a prerequisite for targeted support. Our studies therefore underscore the need for a procedure for standardised grief assessment to ensure optimal allocation of health care services.
The randomised controlled trial in this thesis studied the effects of a bereavement management program in general practice geared to optimise the clinical care for bereaved relatives and ensure appropriate use of healthcare resources. In Study 4, we found indications of an effect of the intervention compared with usual care. GPs in the intervention group more often chose to give information and supportive care and to referral bereaved relatives to a mental health practitioner, whereas GPs in the control group favoured prescription of psychotropic medicine. Yet, the trial also showed low rates of identification of CG. None of the observed differences reached statistical significance, but the findings underpin the need for future studies of GPs’ care for patients facing loss and bereavement.

No other clinical trial on bereavement intervention in general practice was found in the literature, yet earlier studies on bereavement in general practice have pointed to the need of improving assessment and clinical care [16;19-21]. Our clinical trial showed an encouraging impact of the intervention, although the results were not convincing because the study population was too small to obtain a satisfactory statistical precision level or show statistically significant differences. A first step to amending grief reactions is recognition of a treatment-prone condition, which was the focus of our clinical trial; and in this trial, the difficulties in identifying patients with the greatest need for help demonstrate the need for a standardised instrument to be used in a clinical setting for assessing CG. However, the results also underpin the need for more research to validate our findings. There is a need for larger studies to test potential moderators of treatment response and improve identification of CG, as well as optimised planning of treatment of CG in integrated healthcare.
REFERENCES CHAPTER 9


CHAPTER 10

CONCLUSION OF THE THESIS
The following conclusions can be drawn from the findings of this thesis:

**Healthcare utilisation during bereavement:**
Our study on healthcare utilisation suggests a distinct effect on the patterns of healthcare utilisation by spousal bereavement due to cancer. The increase in healthcare utilisation emerged as a characteristic spike-like pattern around the time of the loss, but the rise in healthcare utilisation was evident even before the loss and lasted for months or even years after the loss. This increased pertained to a broad spectrum of health care services.

**Prevalence of bereavement-related impairments:**
A substantial part of deceased cancer patients’ family caregivers develop symptoms indicating CG and depression in relation to their grief reaction. A segment of the bereaved relatives continue to suffer from high levels of distress over a considerable period of time where treatment is required.

**Assessment:**
In the studies of this thesis, professional clinical assessment of the relatives’ grief reaction lacked precision. The problem of identifying mental health disorders among health professionals is not an unfamiliar problem. The studies point to the need of a validated and standardised grief assessment instrument for clinical care and for more training in clinical assessment.
Screening:

Our analyses showed the predictive properties of the Beck’s Depression Inventory in combination with the single item question “Even while my relative was dying, I felt a sense of purpose in my life”. A model for clinical screening of bereaved individuals at risk of developing CG was proposed on the basis of the analyses. Further validation will be needed to fully appreciate the value of this screening tool for clinical work.

Clinical trial:

The randomised controlled trial showed indication of an effect of the bereavement management intervention although none of the results were statistically significant. GPs in the intervention group were more likely to choose information giving, supportive care and referral to a mental health practitioner for patients with a symptom level suggestive of CG than GPs in the control group, who used more psychotropic medicine than the former. These results are encouraging and they underpin the need for further education and training of GPs to provide clinical care for patients facing bereavement.
CONCLUSION OF THESIS

Overall this thesis has shown that spousal bereavement due to cancer has a distinct effect on patterns of healthcare utilization, and a substantial part of bereaved relatives of deceased cancer patients develop CG. At the same time, professional risk assessment of bereavement reactions seems to lack precision and there is a need for a validated and standardised assessment tool. Symptoms of depression right after spousal loss may predict the development of CG in this group of bereaved relatives, but more research is needed to ensure early identification of bereaved relatives at risk. A randomised controlled trial on the management of bereavement care in general practice indicated that the intervention had some effect, and a knowledge update to GPs on CG seemed to increase their information dissemination, supportive care and referral to mental health practitioners of patients with CG compared with the control group. The results testify to the potential for optimising targeted treatment planning for CG in integrated healthcare.
CHAPTER 11

IMPLICATIONS FOR THE MANAGEMENT OF
BEREAVEMENT IN THE HEALTHCARE SYSTEM
PERSPECTIVES

The present thesis offers a research perspective on aspects of bereavement care within the Danish healthcare system on the one hand and a clinical perspective on the diagnosis and treatment for bereaved patients in general practice on the other hand. More specifically, the thesis seeks to describe the impact of bereavement on patterns of health care utilisation and to assess the prevalence of CG. Moreover, a clinical trial tested a program for managing bereavement in primary care with encouraging results.

This thesis contributes with valuable new information about bereaved persons’ care needs and with new clinical knowledge on how to identify those who need such treatment. A bereavement management intervention is proposed for general practice to ensure optimised clinical care, individual treatment planning, correct triage and referral of those in need of specialised care.
FUTURE RESEARCH

The results of the present thesis allow us to propose the following foci for future research on the management of bereavement in the Danish healthcare system:

• Further basic and clinical research into the concept of complicated grief is needed. More cross-cultural data are needed to investigate the construct validity and diagnostic criteria of the concept of CG.

• An important first step in future research would be the further development and validation of a tool to standardise clinical assessment of grief. This grief inventory could be the ICG-R used in this thesis or a newer version of the inventory called the PG-13 (Prolonged Grief – 13).

• There is a need for future research to identify healthcare and patient-related risk factors for bereavement-related impairments and factors associated with a high need for health care among bereaved subjects. Further multivariate analysis of cohort data obtained during the work of this thesis and new clinical and epidemiological studies could help identify sub-groups with a heightened need of targeted clinical care.

• The effects of the intervention in the clinical trial of this thesis should be further scrutinised to reap the full potential of the collected data, and to further develop a clinically relevant bereavement intervention in general practice. Naturally, it is to be wished for that an improved intervention could be tested at a larger scale and with sufficient statistical power to yield a more convincing
result. There is a need for long-term follow-up studies that deploy both clinical and health services-related outcome measures.

- Since the trial showed promising results, questionnaire responses could possibly offer more information about factors that mediate patients’ treatment responses. This knowledge could further inform the coordination and the planning of targeted care.

- Finally, new research projects in clinical care of bereavement should be considered an area of further health services research to ensure coordination of shared care and optimal utilisation of healthcare professionals’ various resources. Special emphasis should be devoted to distinguish between patients with no need for medical care, patients with a need for updated care in general practice and patients with a need for specialised intervention by psychologist or other health care professionals with special skills and knowledge. Furthermore, new research should also address ways to refine and develop clinical care of bereaved persons and treatment of CG.

- Research on the information materials used in the intervention of the clinical trial could inform quality assurance studies and knowledge updates for healthcare professionals to improve their communication about bereavement and to refine the potential of the intervention.
A central task of a highly specialised healthcare system is to continuously adapt to the growing demands for higher quality of health services in the face of limited resources and hence the need to target specialised care to those with the highest need. Furthermore, early diagnosis and planned, focused care to improve prognosis is a prerequisite for optimal clinical care.

This thesis addresses two main issues in the management of bereavement within the healthcare system. It first studies bereaved relatives’ use of health care services after their spouse’s death and explores if the assessment of grief reactions for which treatment is needed may be enhanced to ensure that health care is offered in a targeted manner in conformity with the principles of integrated and shared care. It then deploys a clinical perspective by examining the impact of a grief management program in primary care designed to ensure appropriate clinical treatment and correct triage and coordination of integrated care for those in need of specialised treatment.

The studies of this thesis testify to the need for updated knowledge and training of healthcare professionals as well as for standard assessment tools within bereavement care. One way to accomplish these goals is through the development of clinical guidelines for the provision of health care for bereavement-related distress. Clinical guidelines could ensure consistent and standardised assessment and aid informed individual planning and coordination of clinical care. The real success of this approach requires professional implementation of the clinical guidelines and the integration of clinical care for bereaved patients into pre- and postgraduate training of health professionals in primary care. These were the ideals set out for managing bereavement in the healthcare system at the beginning of this thesis, and our studies may have taken a small step along the road towards this goal.
CHAPTER 12

ENGLISH SUMMARY
This PhD thesis is based on the project “Bereavement Management. Description, assessment and care. A randomised controlled trial”. The thesis features four scientific papers that focus on bereavement management both in a clinical and a healthcare services perspective.

Introduction
Bereavement is a par excellence example of a domain where a high demand for healthcare services remains remarkably unexplored and under-researched and where coordination and integrated healthcare is required to ensure an adequate level of quality of the services delivered. It is estimated that 10-15% of bereaved relatives will develop complicated grief (CG) during the adjustment to their loss, but there is a lack of knowledge about the prevalence of CG in Denmark. Effective treatment of CG has been reported, but early diagnosis and targeted care is challenged by the absence of appropriate screening and assessment instruments. The GP holds the position of healthcare coordinator in the Danish healthcare system, yet training in clinical bereavement care is sparse. Research that explores how GPs may best assume the coordinator’s role in the planning and execution of targeted clinical bereavement care is clearly warranted.

Aims
The overall aim of the present thesis is to address current challenges in bereavement care towards relatives of deceased cancer patients within the context of the Danish healthcare system and, in particular, to explore opportunities for improvements of bereavement care.

The specific aims were:
• To describe the overall impact of spousal bereavement due to a cancer disease on principal areas of healthcare utilization.
• To assess the prevalence of CG and depression among bereaved relatives of cancer patients in palliative care.
• To investigate whether healthcare professionals’ clinical assessment is effective in identifying CG.
• To explore the possibility of developing a screening instrument to identify bereaved relatives at risk of CG.
• To test the effects of a program for bereavement care in general practice designed to optimise the identification and treatment of CG.

Methods
Three different study designs were employed: A nationwide case-control study provided a comprehensive overview of bereaved spouses’ overall healthcare utilisation. The cohort design was applied to describe the prevalence of CG and depression and to identify predictive factors. A randomised controlled trial tested the precision of professional risk assessment and the effect of an intervention with a novel approach to bereavement care in general practice.

Results
The case-control study showed that spousal bereavement due to cancer has a distinct effect on patterns of healthcare utilisation, and that the effect is evident from a few months before the loss to at least two years after the loss. Investigating the grief reaction in the cohorts of bereaved relatives, the study showed that a substantial part of these persons developed CG; yet, professional risk assessment of bereavement reactions lacked precision. Symptoms of depression right after the loss may be a predictor of the development of CG in cancer patients’ bereaved relatives. The randomised controlled trial showed that an intervention towards GPs offering a knowledge update had some effect on CG symptom recognition and treatment.
Conclusion and perspectives

This thesis contributes with valuable new knowledge on which relatives are in need of healthcare during bereavement and how to identify these persons. The studies show that a substantial number of bereaved relatives suffer from CG and depression after their loss. Furthermore, the studies of this thesis indicate that standardised assessment would be valuable in identifying bereaved people in need of help, and updated knowledge and training for healthcare professionals in bereavement care could help ensure better care. These benefits may be obtained through the development of clinical guidelines for the provision of healthcare to alleviate bereavement-related distress. Clinical guidelines could ensure consistent and standardised assessment and aid informed individual planning and coordination of clinical care and, furthermore, secure lean and better integrated healthcare.
CHAPTER 13

DANISH SUMMARY
Dansk resumé

Baggrund
Formål
Det overordnede formal med denne afhandling er at adressere de udfordringer, der er i sundhedssystemets håndtering af sorg blandt efterlevende til kræftpatienter og at undersøge mulighederne for at forbedre behandlingen af sorg i det danske sundhedssystem.

De specifikke formål var:
- At beskrive den indflydelse sorg efter tabet af en ægtefælle til kræft har på det overordnede forbrug af sundhedsydelser.
- At undersøge forekomsten af CG blandt pårørende der har mistet en nærtstående til kræft.
- At undersøge om sundhedsprofessionelles kliniske vurdering af sorgreaktioner effektivt identificerer CG.
- At undersøge mulighederne for at udvikle et screeningsinstrument til tidlig identifikation af CG blandt sørgende pårørende.
- At teste effekten af en klinisk intervention over for sorghåndtering i almen praksis som er udformet med henblik på at sikre tidlig identifikation og behandling af CG.

Metode
Tre forskellige studiedesigns blev benyttet i afhandlingen: En case-kontrolundersøgelse på nationalt plan leverede et omfattende overblik over forbruget af sundhedsydelser blandt sørgende ægtefæller. To kohorteundersøgelser blev benyttet til at beskrive prævalensen af CG og depression og til at identificere prædiktive faktorer. En randomiseret, kontrolleret undersøgelse testede de sundhedsprofessionelles kliniske vurdering af sorgreaktioner samt effekten af en ny intervention i forhold til sørgende i almen praksis.
Resultater
Case-kontrolundersøgelsen viser, at det at miste en ægtefælle til kræft kan have en udtalt effekt på forbrugsmønsteret af sundhedsydelser, og denne påvirkning, som berører flere kerneområder i sundhedssystemet, er tydelig flere måneder før dødsfaldet og indtil mindst to år efter dødsfaldet. Kohorteundersøgelserne viser, at mange efterlevende til kræftpatienter udvikler symptomer på CG, og at de sundhedsprofessionelles kliniske vurderinger af sorgreaktionen mangler præcision. Vores analyser tyder på, at depressive symptomer umiddelbart efter dødsfaldet kan fungere som en prædiktor for CG blandt pårørende til kræftpatienter. Den randomiserede, kontrollerede undersøgelse viste tegn på at interventionen havde en effekt, og på at information om sorg til praktiserende læger kan spille en rolle i deres identifikation af symptomer og behandling af CG.

Konklusion og perspektiver
Denne afhandling bidrager med værdifuld ny viden om hvilke pårørende, der har behov for sundhedsydelser i forbindelse med sorg, og om hvordan sundhedsprofessionelle identificerer disse personer. Studierne i afhandlingen viser, at en væsentlig andel af sorgende pårørende til kræftpatienter lider af CG og depression efter deres tab. Studierne peger endvidere på, at der er behov for et validt og standardiseret instrument til vurdering af sorg i klinikken, som kan sikre, at de personer, der har behov for hjælp, identificeres. Den randomiserede kontrollerede undersøgelse synes samtidig at vise, at information og læring til sundhedsprofessionelle kan resultere i bedre sorgbehandling. Udviklingen af kliniske retningslinjer kan være med til at sikre en højere kvalitet i sundhedsydelserne til behandlingskrævende sorg, at behandlingen målrettes de mennesker, der har det største behov, at behandlingsforløbene er individuelt planlagte, og at behandlingen koordineres mellem forskellige aktører i sundhedssystemet.
REFERENCES LISTED ALPHABETICALLY


Mather MA, Good PD, Cavenagh JD, Ravenscroft PJ. Survey of bereavement support provided by Australian palliative care services. Medical Journal of Australia 2008 Feb 18;188(4):228+.


O'Connor M, Lasgaard M, Shevlin M, Guldin MB. A confirmatory factor analysis of combined models of the Harvard Trauma Questionnaire and the
Inventory of Complicated Grief-Revised: are we measuring complicated grief or posttraumatic stress? J Anxiety Disord 2010 Oct;24(7):672-9.


Praksisplan for psykologihjælp. Region Hovedstaden; 2009.


Bereavement in Healthcare
APPENDIX
PATIENT QUESTIONNAIRE
Bereavement in Healthcare

Sorhåndtering
Efterlevende skema

Dødsfaldet
De første spørgsmål handler om, hvem du har mistet og hvordan du oplevede selve dødsfaldet.

1. Korrekt oplysning?
   - Har du før nylig mistet en nærtstående?
   - Ja
   - Nej - vil bekære, der er sket en fejl.

2. Dato for udfyldelse af skemaet
   - [ ]

3. Hvilken relation havde du til din pårørende? (vælg et kryds)
   - [ ] Mor
   - [ ] Far
   - [ ] Datter
   - [ ] Son
   - [ ] Bror
   - [ ] Ægtefælle/fælleværk
   - [ ] Ven/veninde
   - [ ] Anden relation, skriv evt. hvad:

4. Hvor lang tid inden dødsfaldet, startede det sygdomsforløb, der førte til dødsfaldet? (skriv velighst ca. antal år og måneder. F.eks. 01 år 06 måneder)
   - [ ] År
   - [ ] Måneder

5. Hvor lang tid inden dødsfaldet, blev du klar over, at din pårørende ville da af sin sygdom? (skriv velighst ca. antal år og måneder. F.eks. 01 år 06 måneder)
   - [ ] År
   - [ ] Måneder

6. Stod du selv før en del af plejen af din pårørende inden dødsfaldet? Første stod for medicin, hjælp med at give bade, tage tøj på eller andet? (Sæt et kryds)
   - [ ] Ja
   - [ ] Nej
   - [ ] Ikke relevant

7. Hvor belastende oplevede du selve dødsfaldet?
   - [ ] Skit ikke
   - [ ] Nøgten
   - [ ] Vinket meget

8. Hvordan oplever du, at du har klaret sorgen indtil nu?
   - [ ] Meget godt
   - [ ] Nogenlunde
   - [ ] Meget dårligt

9. Hvordan forventer du, at du vil klare sorgen fremover?
   - [ ] Meget godt
   - [ ] Nogenlunde
   - [ ] Meget dårligt

10. Selv i svære tider, som i forbindelse med dødsfaldet, kan jeg finde en indre mening med mit liv?
    - [ ] Overhovedet ikke
    - [ ] Nøgten
    - [ ] Vinket meget

11. Selv i forbindelse med dødsfaldet oplevede jeg, at der var et formål med mit liv?
    - [ ] Overhovedet ikke
    - [ ] Nøgten
    - [ ] Vinket meget

12. Har du indenfor disse seneste 12 måneder været ute af følgende: (Sæt gerne flere kryds hvis det er relevant)
    - [ ] Anden alvorlig sygdom blandt dine nærtstående
    - [ ] Andre dødsfald blandt nærtstående
    - [ ] Separation/fælleværk/lyst parforhold
    - [ ] Grav overlast (f.eks. trafikulykke, brand, overfall, vold eller lignende)
    - [ ] Mislykkede fejl i arbejde
    - [ ] Stærkt forringede økonomiske forhold
    - [ ] Mange eller svære konflikter med samlever/familie eller venner
    - [ ] Mange eller svære vanskeligheder på arbejde
    - [ ] Andet. Skriv evt. hvad:
      - [ ] Inet af ovenstående
Sorghåndtering
Efterlevende skema

Heldradsstatus
De næste spørgsmål handler om, hvordan du oplever dit helbred.

1. Har du siden dødsfaldet modtaget hjælp fra et eller flere af de følgende steder?
   □ Egen læge
   □ Hospitalet/afdelingen hvor min påværende døde
   □ Et Palliativt Team
   □ Hospice
   □ Præst
   □ Psykolog
   □ Sagsbehandler
   □ Kraftens Bekræmpelse Kådgruppen
   □ Oggruppe
   □ Andre. Skriv evt. herven: __________________________
   □ Ingen af ovenstående

2. Har du indenfor de seneste 12 måneder fået konstateret en af de følgende
   sygdomme af en læge? (Sæt gerne flere kryds, hvis det er relevant)
   □ Kraftsygdom
   □ Forhuket blodtryk, hjertekræmpe, blodbrøb, hjertefyldning
   □ Diabetes/skægvyge
   □ Bronskits, store lungener, rygerlungen, KOL eller astma
   □ Slægplis, ledledgvis, diskosynep, rygssygdom, dårlig ryg
   □ Psykiatrisk sygdom, mentale forstyrrelser
   □ Allergi
   □ Migræne, hyppig hovedpine
   □ Osteoporose/knoglerkæde
   □ Andre. Skriv hvad: __________________________
   □ Ingen/ikke relevant

Hvordan synes du, at dit helbred er alt i alt? (Sæt kun én kryd)
   □ Fremragende
   □ Vægtig godt
   □ Godt
   □ Minde godt
   □ Dårligt

Sorghåndtering
Efterlevende skema

Sammenlignet med før et år siden, hvordan er dit helbred alt i alt nu?
   □ Meget bedre nu end for et år siden
   □ Højest bedre nu end for et år siden
   □ Noviskende det samme
   □ Meget dårligere nu end for et år siden
   □ Højest dårligere nu end for et år siden

Aktiviteter i hverdagen. Er du på grund af dit helbred begrænset i disse aktiviteter?
   □ Ja, meget begrænset
   □ Ja, lidt begrænset
   □ Nej
   □ Slet ikke begrænset

A.  Krævende aktiviteter, som f.eks. løbe, løfte vene ting, deltag i anstrengende sport
   □ □ □ □

B.  Lettere aktiviteter, såsom at flytte et bord, stævse
   □ □ □ □
   eller cykle?

C.  At løfte eller bare dagligvarer?
   □ □ □ □

D.  At gå flere stager op ad trapper?
   □ □ □ □

E.  At gå en etage op ad trappe?
   □ □ □ □

F.  At børge sig ned eller gå ned i knæ?
   □ □ □ □

G.  Gå mange kilometers?
   □ □ □ □

H.  Gå nogle hundrede meter?
   □ □ □ □

I.  Gå 100 meter
   □ □ □ □

J.  Gå i bad eller tage bad?
   □ □ □ □

Har du indenfor de sidste 4 uger, haft nogen af følgende problemer med dit arbejde eller andre
aktiviteter på grund af dit fysisk helbred?

Besvar venligst følgende med én kryd ved for hvert spørgsmål.
   □ Ja
   □ Nej

A.  Jeg har skitted 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 min tid til at bruge arbejde eller andre
   aktiviteter, jeg har kunnet udføre
   □ □ □ □

D.  Jeg har haft behov for at udføre mit arbejde eller andre aktiviteter
   f.eks. krevede det en ekstra indsats
   □ □ □ □
**Sorghåndtering**
Efterlevende skema

### Fysiske symptomer
De næste spørgsmål handler om andre fysiske symptomer og hvor meget, du er generet af dem.

<table>
<thead>
<tr>
<th>Sæt kan ét kryds ud for hvert udsagn</th>
<th>Slet ikke</th>
<th>Lidt</th>
<th>Noget</th>
<th>En hel del</th>
<th>Virkelig meget</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Hovedpine?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 Svimmelhed eller tiløb til at besvane?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Smerter i hjerte eller bryst?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 Lavvækkende nysgerrighed?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 Karme eller uro i naven?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 Muskelstrammer?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7 At du har snært ved at få vejret?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8 Afstand af varme eller kulduforrensmelser?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9 Følelse af olie eller en smurtende forrensmelser i knopen?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10 En kump i halsen?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11 At du føler dig svag i knopen?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12 At dine arme eller ben føles tunge?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Den følelsesmæssige reaktion
De næste spørgsmål handler om din følelsesmæssige reaktion efter dødsfaldet.


1. **Tristhed**
   - Jeg føler mig ikke trist
   - Jeg er et lille trist
   - Jeg er trist helt dagen
   - Jeg er så trist og ked af det, at jeg ikke kan holde det ud

2. **Pessimisme**
   - Jeg er ikke bekymret for min fremtid
   - Jeg er mere bekymret for min fremtid, end jeg plejer
   - Jeg forventer, at min fremtid vil adskille sig i negativ retning
   - Jeg føler, at fremtiden er hårds, og at det kan blive værre

3. **Tidligere nederlag**
   - Jeg føler mig ikke mislykket
   - Jeg har klaret mig dårligere, end jeg burde
   - Jeg har mange nederlag bag mig
   - Jeg føler mig som en total failso

4. **Manglende glæde**
   - Jeg oplever lige så stor glæde ved tilværelsen, som jeg plejer
   - Jeg glæder mig ikke så meget over tilværelsen, som jeg plejer
   - Jeg har meget lidt fornøjelse af de ting, jeg tidligere kunne glæde mig over
   - Jeg har slægt ingen fornøjelse af det, jeg tidligere kunne glæde mig over

5. **Skyldfølelse**
   - Jeg placer et specielt af dårlig samvittighed
   - Jeg har dårlig samvittighed over mange ting, jeg har gjort eller burde have gjort
   - Jeg har dårlig samvittighed det meste af tiden
   - Jeg placeret sinfrust af dårlig samvittighed

6. **Følelser af at blive straffet**
   - Jeg føler ikke, at jeg bliver straffet
   - Jeg føler, at jeg kan blive straffet
   - Jeg forventer at blive straffet
   - Jeg føler, at jeg bliver straffet
7. Negativ selvfældelse
   0. Jeg føler mig ikke anderledes omkring mig selv, end jeg hele tiden har gjort
   1. Jeg har været min selvtilid
   2. Jeg er trist hele tiden
   3. Jeg kan ikke lide mig selv
8. Selvkritik
   0. Jeg er ikke mere selvstændig, end jeg plejer
   1. Jeg er mere kritisk over for 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
9. Selvmodstærk
   0. Jeg har ingen tankar om selvmod
   1. Jeg har tankar om selvmod, men jeg kunne ikke tænke mig at gøre det
   2. Jeg har lyst til at begå selvmod
   3. Jeg ville begå selvmod, hvis lejligheden bed sig
10. Grad
    0. Jeg grader ikke mere, end jeg plejer
    1. Jeg grader mere, end jeg plejer
    2. Jeg grader øverst over selv den mindste ting
    3. Jeg har lyst til at græde, men kan ikke
11. Uro
    0. Jeg føler ikke mere uro, end jeg plejer
    1. Jeg føler mere uro, end jeg plejer
    2. Jeg føler så meget uro, at jeg har svært ved at forholde mig rolig
    3. Jeg føler så meget uro, at jeg er tvivlent til hele tiden at bevæge mig eller foretage mig noget
12. Mangel på engagement
    0. Jeg føler mig ikke anderledes omkring mig selv, end jeg hele tiden har gjort
    1. Jeg er mindre interessert 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
13. Ubeslutsomhed
    0. Jeg er lige så god til at træffe beslutninger, som jeg plejer
    1. Jeg finder det vanskeligt at træffe beslutninger end tidligere
    2. Uds er meget sværere for mig at træffe beslutninger, end det plejer at være
    3. Jeg har svært ved overbevist at træffe beslutninger
14. Fælles af selvfærd
    0. Jeg føler mig ikke værdifuld
    1. Jeg føler mig ikke så værdifuld og andig som tidligere
    2. Jeg føler mig værdifuld, sammenlignet med andre mennesker
    3. Jeg føler mig fuldstændig værdifuld

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 forestige mig rigtig meget
    3. Jeg har ikke energi til noget som helst
16. Ændringer i søvnvaner
    0. Jeg har ikke oplevet ændringer i mine søvnvaner
    1. Jeg har sovet noget mindre, end jeg plejer
    2. Jeg har sovet noget MERE, end jeg plejer
    3. Jeg har sovet meget MERE, end jeg plejer
    4. Jeg har sovet det meste af dagen
    5. Jeg vækker 1-2 timer for tidligt og kan ikke faa sove igen
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
18. Ændringer i appetit
    0. Jeg har appettet uden forst
    1. Jeg har sovet noget MINDER appetit, end jeg plejer
    2. Jeg har sovet noget MERRE appetit, end jeg plejer
    3. Jeg har sovet meget MERRE appetit, end jeg plejer
    4. Jeg har sovet det meste af dagen
    5. Jeg har brødt til med hele tiden
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 i lang tid
    3. Jeg kan ikke koncentrere mig om noget som helst
20. Træthed og udmattelse
    0. Jeg er ikke mere træt eller udkart, end jeg plejer at være
    1. Jeg bliver letten træt og udkort end tidligere
    2. Jeg er for træt og udkort til at gøre mange af de ting, jeg plejer at gøre
    3. Jeg er for træt og udkort til at gøre det, jeg plejer at gøre
21. Tab at interesse for sex
    0. Jeg har ikke ligg mærke til nogen ændringer i min interesse for sex
    1. Jeg er mindre interessert i sex, end jeg plejer
    2. Jeg er meget mindre interessert i sex nu
    3. Jeg har fuldstændig tabt interesse for sex
    4. Ikke relevant
## Sorhåndtering

*Efterlevende skema*

### Tanker om dødsfaldet

*De næste spørgsmål vedrører oplevelser og tanker om dødsfaldet.*

Læs hvert udsagn nedenfor og angiv velegnet, hvor ofte du har oplevet de pågældende tanker og følelser om dødsfaldet indenfor den seneste uge.

<table>
<thead>
<tr>
<th>Bror venligst følgende med ét kryds</th>
<th>DET IKKE</th>
<th>SJÆLLERT</th>
<th>SOMMETID</th>
<th>OFTE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Jeg tanke på det, selvom jeg ikke ansku det</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>2. Jeg undgår at lade mig blive følelsesnævnt påvirket af det, når jeg tanke på det eller blev med om det</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>3. Jeg forsøgte at skruvne tanker om det ud af min bevidsthed</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>4. Jeg havde problemer med at falde i søvn, eller kunne ikke sove, på grund af billede eller tanker om det, som dukkede op i min bevidsthed</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>5. Stærke følelser om det bøjede frem</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>6. Jeg drømte om det</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>7. Jeg holdt mig væk fra de ting, som kunne minde mig om det</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>8. Det fælles uvejeligt, eller som om det stod ikke var sket</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>9. Jeg bestræbe mig på ikke at tale om det</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>10. Billede af det blev ved med at dukke op i min bevidsthed</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>11. Andre ting blev ved med at finde mig i omdøde</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>12. Jeg vari klor over, at jeg stadig havde mange følelser omkring det, men jeg undlod at forblive mig til dem</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>13. Jeg forsøgte at lade være med at tanke på det</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>14. En hvilken som helst påmindelse bragte mine følelser om det tilbage</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>15. Jeg oplevede nærmest at være følelsesløs omkring det</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

### Andre psykiske reaktioner

*De næste spørgsmål vedrører andre psykiske reaktioner, du kan have oplevet efter dødsfaldet. Spørgsmålene skal hjælpe os forstå dine reaktioner bedre.*

Læs hvert udsagn nedenfor og angiv velegnet, hvor ofte du har oplevet de pågældende tanker og følelser inden for de sidste 4 uger.

<table>
<thead>
<tr>
<th>Såd kun at kryds ud for hvert udsagn</th>
<th>SJÆLLERT</th>
<th>LIKT</th>
<th>NOGET</th>
<th>EN HEL DEL</th>
<th>VIRELSK MÅGET</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. At du pludselig bliver bange uden grund?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>2. Nervøst eller indre uro?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>3. Anfald af rædsel eller panik?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>4. At bekymre dig for meget?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>5. En følelse af at blive erfarlig eller alenat?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>6. Temperamentsudbrud, som du ikke kan kontrollerede</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>7. At have trang til at šåe, såre eller skade nogen?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>8. At have trang til at ødelegge eller såe ting i styrken?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>9. At komme let i skærmen?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>10. At du røber eller småler ting?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

### Social støtte

*Spørgsmålene på næste side omhandler dit forhold til andre mennesker.*
## Bereavement in Healthcare

**Sorghåndtering**

Efterlevende skema

Angiv venligst hvor ofte du oplever det, som spørgsmålet beskriver. Såt kun ét kryds for hvert udsagn.

### How often do you experience the following?

<table>
<thead>
<tr>
<th>Sparsom</th>
<th>Aldrig</th>
<th>En gang medlem</th>
<th>Jævnligt</th>
<th>Ofte</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1. **At andre mennesker er varme og kærlige forover dig?**
2. **At andre mennesker er vennlig forover dig?**
3. **At andre mennesker viser sympati for dig?**
4. **At andre mennesker viser forståelse for dig?**
5. **At andre mennesker er vilde til at lytte til, hvad du har på hjerte?**
6. **At andre mennesker får dig til at føle dig veltilpas?**
7. **At andre mennesker "giver dig et skub i den røgke længing"?**
8. **At andre mennesker giver dig en opmuntring?**
9. **At andre mennesker står dig i dine tanter og handlinger?**
10. **At andre mennesker holder mødet oppe hos dig?**
11. **At de kan stole på andre mennesker?**
12. **At de "smooter forbi" for at besøge dig?**
13. **At folk tager dig til at kontakte dig bare for at snakke?**
14. **At du foretager dig ting, f.eks. indkøb, biografkort eller udfører sammen med andre mennesker?**
15. **At andre mennesker spørger om du har tvært til at deltage i det, de foretager sig?**
16. **At du går ud med andre børn for barnets skyld?**
17. **At andre hjælper dig med småt eller mindre opgaver?**
18. **At andre laver dig småting, f.eks. mel, koke, skrive, skrivekort eller lignende?**
19. **At andre laver dig mindre arbejde?**
20. **At andre giver dig oplysninger eller gode råd?**
21. **Hvis du får brug for det, laver andre mennesker væsentlige ting til dig?**
22. **Hjælper andre mennesker dig, hvis du får brug for det, f.eks. når du er syg, hvis du mangler kærlighed eller hvis du har brug for, at nogen tager med dig et eller andet sted?**

### Personal oplysninger

Til slut vil vi bede dig besvare et par spørgsmål om dig selv.

1. **Hvad er din ægteoldsbeløbelse status?**
   - Eng (enke/tekken) [ ]
   - Eng (skilt, separeret, aflivet fast samvivshold) [ ]
   - Eng (ikke tidligere gift eller sæmlende) [ ]
   - Samlevende [ ]
   - OBR [ ]
   - Andet. Skriv evt. hvad: ____________________________

2. **Har du børn?**
   - Ja [ ]
   - Nej [ ]
   - Hvis ja, skriv venligst antal hjemmelæbende børn: ____________________________

3. **Hvordan er din behandlingshistorie?**
   - Ingen [ ]
   - Er under uddannelse/studenter [ ]
   - Specialarbejder uddannelse [ ]
   - Kortvarig uddannelse (op til 1 år) [ ]
   - Pædagog i undervisning, handel, kontor (f.eks. lærling- eller dig-uddannelse) [ ]
   - Kort videregående uddannelse under 3 år (f.eks. politibetjent, sexus-assistent m.v.) [ ]
   - Lærling videregående uddannelse 3-4 år (f.eks. slokemærker, journalist, socialrådgiver) [ ]
   - Lang videregående uddannelse 5 år eller mere (f.eks. civilingeniør, læge, biolog) [ ]
   - Andet. Skriv evt. hvad: ____________________________

4. **Hvor stærkt er din nuværende fremtidsevalueringe Brasilienområde for slutt sidste år?**

   - Under Kr. 95.000 [ ]
   - Kr. 100.000 - 249.000 [ ]
   - Kr. 250.000 - 449.000 [ ]
   - Kr. 450.000 - 700.000 [ ]
   - Over Kr. 700.000 [ ]
   - Ved ikke [ ]
5. Hvaen var din erhvervsmæssige situation før din pårørende døde? (seet kun ét kryss)

☐ I fuldtidsarbejde (37 timer eller derover)
☐ På nedlagt arbejde (færre end 37 time)
☐ Under uddannelse
☐ I fælles job eller lignende
☐ På olov (eks. plejeplev)
☐ Hjemmekørende
☐ Arbejdsløs
☐ Sygeanlæg
☐ Under omsorg eller revalidering
☐ Foridsrehabilitering
☐ Pensionist/efterlønsomtager
☐ Arbejdsløs med understøttelse
☐ Ø økonominhjælp
☐ Andet. Skriv evt. hvad

Skriv meget gerne andre erfaringer eller tanker om hvordan du oplever din sorgreaktion nedenfor. Det er en stor hjælp for os.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Forhåbentligt bødning
GP QUESTIONNAIRE
Bereavement in Healthcare

Kære kollega,

Med dette spørgeskema ønsker vi at indhente oplysninger fra praksisværende læger til den generelle udfoldelse af projektet "Sorghåndtering i sundhedsvesenet.

Spørgeskemaet handler om: absence på grund af sorgfortøbet som henvises til i følgende.

Vejledning i udfoldelse af spørgeskemaet:

Læs venligst nedenstående indehvis du går i gang.

Når du udfører spørgeskemaet, beder vi dig være opmærksom på følgende:

Bemyndiget en sort eller blå kuglepenn, da svarene skal aflæses maskinelt.

Svar så vist muligt på alle spørgsmålene.

Følg vejledningen i spørgeskemaet og sæt kryds i ud for det svar, der umiddelbart passer bedst for dig.

Sæt kun kryds i et afkrydningshelt, medmindre andet er anført.

Hvis du leverer en forkert afkrydning, så fjald boksen helt ud og sæt krydset i den rigtige boox.

Når du har udført spørgeskemaet, beder vi dig returnere det i sæk'en. Førsten er betalt.

Har ud spørgsmål til spørgeskemaet, kontakt da venligst:

Projektoillustrator, psykolog Mai Britt Gulden
 Forskningsenheden for Almen Praksis
 Aarhus Universitet
 Bartholins Allé 2, 8000 Aarhus C
 Tlf: 89429059
 E-mail: mgb@gdm.au.dk

Mange tak for din hjælp!
Sorhåndtering
Læge skema

Hvis der har været kontakt med patienten om sorforløbet, beder vi dig svare på nedenundervisninger spørgsmål om kontaktlen.

Hvis der ikke har været kontakt med patienten om sorforløbet, går det venligst til spørgsmål nr. 20.

Kontakt med patienten i sorforløbet

6. Har du/praksis udført kontakt med patienten (f.eks. en opgivning) i forbindelse med sorforløbet? (Sæt et kryds)
   □ Ja
   □ Nej - hvis nej, beder vi dig anføre hvornår nedenfor
   □ Jeg syntes ikke, det var relevant i forhold til mit kendskab til patienten
   □ Det faldt mig ikke ind i det konkrete forløb
   □ Det gør jeg generelt aldrig
   □ Andet. Anfør gerne begrundeni

7. Har du/praksis taget initiativ til at tale med patienten om sor (f.eks. i en konsultation)? (Sæt et kryds)
   □ Ja
   □ Nej - hvis nej, beder vi dig anføre hvornår nedenfor
   □ Jeg syntes ikke, det var relevant i forhold til mit kendskab til patienten
   □ Det faldt mig ikke ind i det konkrete forløb
   □ Det gør jeg generelt aldrig
   □ Andet. Anfør gerne begrundeni

8. Har patienten selv optaget kontakt med dig/praksis med henblik på at tale om sorforløbet (f.eks, opgivning, tid i konsultation m.v.)? (Sæt et kryds)
   □ Ja
   □ Nej

9. Efter din vurdering, hvor ofte har du/praksis haft kontakt med patienten om symptomer der kunne relateres til selsorforløb? (Sæt et kryds)
   □ Ofte
   □ En del (gange)
   □ Få (gange)
   □ Aldeles ikke (gange)

10. Hvor meget tid fyldte følgende aspekter i din kontakt med patienten om sorforløbet:
    Sæt kun et kryds ud for hvert udsagn
    Meget tid □ Nogt tid □ Litt tid □ Ingen tid □ Ikke relevant □
    A Fysiske symptomer (f.eks. åndedrejning, aspektionsfædret, bubre, kravlen)
    B Psykiske symptomer (f.eks. angst, depressions symptomer, vrede)
    C Kognitive symptomer (f.eks. koncentrationssvag, tankerystelser)
    D Sociale symptomer (f.eks. tilbageværende kontakt, relationer til venner/familie)
    E Eksistentielle problemer (f.eks. overvejelser om liv eller død eller fremtid)
    F Konkret problem (f.eks. eksempl, få hverdagen til at fungere)
    G Andet. Angiv venligst hvid:

11. Efter din lægesaglig vurdering, i hvilket grad deltes sig, at der har været funktionsafslag eller psykosomatiske støjler i sorforløbet: f.eks. diffusion smerte, hygnesvag, kognitive fornemmelser som støjler, press, vrede, følelseslighed m.v.? (Sæt et kryds)
    □ Ofte
    □ En del (gange)
    □ Få (gange)
    □ Aldeles ikke (gange)
    □ Det er ikke relevant

References listed alphabetically
12. Hvordan vil du karakterisere den sorgsreaktion, patienten gennemgår/gik? (Din egen klinisk vurdering ud fra det kendskab til patienten og sorgforløbet) (Sæt et kryd):
- 3: Kompliceret reaktion. Der er tilstødelse angst, depression, selvendstærkelse, social isolation e.l.lign.
- 4: Ved ikke - har ikke tilstrækkelig kendskab til patientens sorg forløb

13. Henviste du/praksis patienten til videre professionel hjælp i sorgforløbet?
- Nej, det vurderede jeg ikke, der er ikke noget for det
- Nej, jeg foretog det, men patienten var ikke interesseret
- Ja, vi beder dig anføre hvem nederst (gemme flere krydder)
  - Psykolog
  - Psykiater
  - Sågsbehandler
  - Andre. Anfør venligst hvem:

14. Hvorpraksis henviste patienten til videre professionel hjælp i sorgforløbet, beder vi dig nederst for anføre hvortil (Sæt gerne flere krydder)
- På grund af psykiske symptomer (f.eks. angst, depression)
- På grund af sociale omstændigheder (f.eks. manglende ressourcer hos pårørende)
- Efter patientens eget ønske
- På grund af ringe kendskab til patienten
- På grund af manglende erfaring med sorgproblematiske
- På grund af egen tidsmangel
- Andre. Anfør venligst hvem:

15. Informerede du/praksis patienten om andre muligheder for hjælp (and. psykolog/psykiater) i sorgforløbet?
- Nej, det vurderede jeg ikke, der var behov for
- Nej, jeg har ikke tilstrækkeligt kendskab til andre muligheder for hjælp
- Ja, jeg foreslog det, men patienten var ikke interessert
- Ja. Vi beder dig anføre hvem nederst:
  - Kræftens Bastemøde Rådgivningscenter
  - Lokal sundhedsgruppe
  - Præst
  - Kommunel forsikring
  - Andre. Anfør venligst hvem:

16. Fører du din viden og tildelighed til at hjælpe patienten med sorgen:
  Besvar venligst følgende med et kryds ud for hvortil spørgsmålet:
  I høj grad ▼ I nogen grad ▼ I nogen grad ▼ Står ikke ▼
  A. Jeg føler, at min faglige viden om sorg var
     tilstrækkelig til at hjælpe patienten
  B. Jeg føler, at mine tildeligheder i sorgshåndtering
     var tilstrækkelige at hjælpe patienten

17. Gav du/praksis behandling til patienten for sorgen?
- Nej, det vurderede jeg ikke, der var behov for
- Nej, jeg foreslog det, men patienten var ikke interessert
- Nej, men set i almindelighed kunne det måske have været indikeret
- Ja, vi beder dig nederst for at anføre hvilken behandling (gemme flere krydder)
  - På grund af sorgforløbet
  - Adm konsultation med en hankon på, at yde støtte og/eller medføre sorgen
  - Smaaletrappe (6501 ydelser)
  - Medicinale behandling (f.eks. sedativ, antidepressiva)
  - Andre. Anfør venligst hvad
18. Hvis medicinsk ret behandling blev været set for sorgen, angiv venligst hvilken:
☐ Antidepressiv behandling
☐ Sovepiller
☐ Angststillingende
☐ Andet. Anfør venligst hvad.

19. Gjorde du dig særlige diagnostiske overvejelser i din kontakt med patienten om sorgforløbet?
☐ Nej, det var ikke udfordring.
☐ Ja, jeg har set i bakspeklet kunne de måske have været indlæst.
☐ Ja - vi beder dig anføre, hvad du så gavt diagnosticer (ogle flere krydder)
☐ Depression
☐ Angst
☐ Belastningssans
☐ PTSD
☐ Selvmedierende
☐ Socialfravært
☐ Andet. Anfør venligst hvad.

De sidste 2 spørgsmål er knyttet til interventionspraksis. Det vil
fremgå af følgende, om din/praksis er interventionspraksis. Vi
beder altså interventionspraksis om at besvare de 2 spørgsmål.

Sorgmaterialet

Sorgmaterialet i projektet bestod af: Patientens risikoscore, et lamineret dialog
ark samt en kort artikel om identifikation af behandlingskrævende sorg.

24. Laen som det materiale der blev sendt fra sorgprojektet?
Sæt et kryds ud for hvert spørgsmål:
☐ Ja
☐ Nej
A Patientens risikoscore
B Dialog ark
C Sorg arkaen

25. Betydelsefuld materialet der blev sendt fra sorgprojektet?
Sæt et kryds ud for hvert spørgsmål:
☐ Ja
☐ Nej
A Patientens risikoscore
B Dialog ark
C Sorg arkaen

Tak for hjælp.
INFORMATION MATERIALS
Sorghåndtering
i almen praksis

Fire konsultationer til sorghåndtering
Tidsintervallet mellem konsultationerne er ca. 2-4 uger men vurderes individuelt på baggrund af sorgens værnhedgrad.

1. Konsultation: Italesættelse af sorgen
   - I den første tid handler spørgsten mest om at være lyttende og forstående.
   - Anerkendt at sorg er smertefuld og "hårdt at arbejde".
   - Spørg til hvordan sorgen opleves og hvem der yder praktisk og følelsesmæssig støtte.
   - Få en vurdering af belastningsgraden i sorgreaktionen: "På en skala fra 1 – 10, hvor 1 er mindst og 10 er mest, hvor belastende oplever du sorgen?"

2. Konsultation: Dynamik i sorgreaktionen
   - Spørg til hvordan sorgen opleves nu og til belastningsgraden i sorgreaktionen (samme skala som ved 1. konsultation).
   - Foretag sammen med patienten en vurdering af om hverdagen fungerer (den følelsesmæssige regulering ml. tab og opretholdelse af hverdagsliv).
   - Drøft om der er bevægelse i reaktionen hen mod accept af dødsfaldet.
   - Afdrift opfølgende konsultation afhængig af reaktionen. Ved høj selvvurderet belastning, screeningssvar med høj risiko samt manglende bevægelse i sorgreaktionen aftales tættere opfølgning.

3. Konsultation: Følelsesmæssig regulering
   - Spørg til belastningsgraden i sorgreaktionen (samme skala som ved 1. konsultation).
   - Vurder eventuelt kompliceret sorgreaktion på baggrund af følgende tegn:
     - Belastningsgraden er ikke reduceret siden dødsfaldet
     - Depression, angst, selvindsættelse, belastningsreaktion, misbrug
     - Ingen bevægelse i reaktionen hen mod accept af dødsfaldet
     - Den følelsesmæssige regulering udebliver (ml. tab og hverdagsliv)
     - Udtalt tillægsfærdighed fra social kontakt
   - Afdrift evnt. opfølgende konsultation afhængig af reaktionen eller
   - Viderehenvisning til psykologbehandling ved kompliceret sorg (Obs: Tab af nærtstående giver ret til psykologhenvisning under sygevæsningen).

4. Konsultationen: Vurder kompliceret sorgreaktion
   - Spørg til belastningsgraden i sorgreaktionen (samme skala som ved 1. konsultation).
   - Vurder der tog på kompliceret sorgreaktion (so under 3. konsultation).
   - Vurder om patienten skal viderehenvises til psykologbehandling eller fortsat modtage støtte i almen praksis.

Læs evtl. mere om støtte, tidlig opsporing og identifikation af symptomer på kompliceret sorg på bagsiden og i vedlagte artikel Sorghåndtering.
Hvornår er sorg behandlingskrævende?


Symptomer på kompliceret sorg

**Kompliceret sorg**

**Forløb:** Problematisk accept/fornægelse af dødsfaldet, ingen gradvis reduktion af følelsesmæssig intensitet, vedvarende chok/smerter, dysfunktionel kognitiv tilpasning (fornægelse).

**Physiske symptomer:** Depression, angst, posttraumatiske stress, selvmordstanker, nyopstået/forværret misbrugsproblematik, vedholdende påtrængende erindringer, vedvarende stærk løjsgel, meningsløshed.

**Fysiske symptomer:** Søvn- og spisesforstyrrelser, tendens til somatisering.

**Sociale konsekvenser:** Isolation, udståt tilbagegrænsning fra social kontakt, tab af interesse i daglige funktioner og arbejde. Besvær med at opretholde normal hverdag.

Den onde cirkel:

Længelse/smerter  
"Jeg serer hver dag uafhængigt engest.

Påtrængende koldhjertet  
"Forlænget hukker jeg, at han er i dådel og at han er i sorgen.

Desillusionering  
"Jeg har ikke mere tilfælde fra de særlige følelses.

Bemættelse  
"Jeg heller mig selv ind, at han har et bedre liv og kunne tilbagegå engest.

Dysfunktionel kognition  
"Jeg har ikke mere tilfælde fra de særlige følelses.

Sorgstøtte i sorgsforlængelse, behandling og støtte. Et randomiseret kontrollerede studie.
Tlf. 60420020. Email: m.gudzi@hum.au.dk
Sorghåndtering i almen praksis

Hvad er sorg?

Sorg defineres som den fysiske og psykiske reaktion på tabet af en nærtstående, man har knyttet emotionel bindelse til. Tabet fører til en periode med intens og pinefuld sorg som kan være, og hvor længe tid den varede. I perioden med meget intens og pinefuld sorg vil mange komme i tab af, hvordan deres sorg er behandlingsfarlige og howe kendes disse symptomer (figur 1).

Kliniske problemstillinger

Der foreligger nu evidence for, at op mod 20% af dem, der har mistet en nærtstående, oplever komplikeret sorgsreaktion. Etter 12% vil månede kunne problemer med specialiseret psykologisk behandling varer. Derudover synes det, at de som udvikler en komplikeret sorgsreaktion, har flere psykologiske problemer (figur 1).

Additive

Depression, fortæthed, modløshed
Angst, frygt, skræk
Skæld, vilkårsløshed
Vrede, stress, irritabilitet
Tab af kærlighed - uværet
Alkoholisme
Lignende - alt forvirret af længsr

Afledningsmønster

Agitation, ansigtsflød, nestesløshed
Tæthed, overskuddet
Søvnfærd
Gravid, færdighed
Social tilpasningsskrænkelse

Figur 1: Sorg symptomer

Ny teori og viden

En ny teori om sorg har været, at forklaring af sorg er målrettet en nødvendig for at man kan "komme i sorgen". Der er dog tabet, der tyder på, at det er nødvendigt for alle.

Sorg har været opgjort af myrer, men indikerer det, at sorgskrivebog er det samme, som vi kendte den nu videns om sorg. Forskning tyder på, at det er nødvendigt, for at en person kommer videre efter at have mistet en nærtstående. Det gennemgår de alle sorges tankes og følelser vil ikke altid have en positiv effekt, og for nogle vil det gøre ordet værre. Vi skal altså se på en ny model for "sorgsreagering".

Tosporsselskab – adapisv sorgsreagering

Tosporsmodellen tydeligvis, at håndtering af sorg er meget nødvendigt i tiden, men et problem er at få en ordning for at få et ordning for sorg. Tosporsmodellen fungerer som en aktiv, åbentbevægelig proces, som kan løse et behov for at få en ordning for sorg. Det er derfor vigtigt at ”hjælpe med i de spørgerne”.
Adaptiv søgbehandlingsansvar er en fremadgående dynamisk process, som kræver en kombination af emotio- 
nelle behandlingsfragen af tabet og afle-
ning/affyring af det tunge emotionelle ar-
bejde. Det er altid ligesom sagt i at "håbe ret fra 
den emotionelle søgbehandling, som det er at 
søgeforhøre og bistå tabet. På samme tid er der 
ældre for knappe concrete dyrkemåder, der er 
rigtige for at lære og leve livet uden afhængige, 
som f.eks. at lære med, holde styr på økonomiern 
hos bolige. Senere af god adfærd er derved 
en noskent konfrontation med tabet og en aktiv 
aflejring af de vigtige tabet og tanker. Derfor 
afhævning i at benytte de vigtige for at 
handle med at få en adgang til prefektet 
hveranda og aflejring.

Hveranda er et behovsforløbende behovsforløbende begreb, der refererer til den 
vigtige rolle af at give en adgang til 
hveranda og aflejring. Dette forløbende 
behovsforløbende begreb, der refererer til 
den emotionelle søgbehandling, som det er at 
søgeforhøre og bistå tabet, på samme tid er der 
ældre for knappe concrete dyrkemåder, der er 
rigtige for at lære og leve livet uden afhængige, 
som f.eks. at lære med, holde styr på økonomiern 
hos bolige. Senere af god adfærd er derved 

**Figur 2.** Tabets varierende modeller

**Figur 3.** Fra en søgbehandling

Diverse behandlingsmål

**Figur 4.** Værdiopbygning af valg og søgbehandling

**Figur 5.** Hvor kommer søgbehandling fra?

**Figur 6.** Hvor kommer søgbehandling fra?

**Figur 7.** Hvor kommer søgbehandling fra?

**Figur 8.** Hvor kommer søgbehandling fra?

**Figur 9.** Hvor kommer søgbehandling fra?

**Figur 10.** Hvor kommer søgbehandling fra?

**Figur 11.** Hvor kommer søgbehandling fra?

**Figur 12.** Hvor kommer søgbehandling fra?

**Figur 13.** Hvor kommer søgbehandling fra?

**Figur 14.** Hvor kommer søgbehandling fra?

**Figur 15.** Hvor kommer søgbehandling fra?