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PARENTS WHO HAVE LOST A SON OR DAUGHTER THROUGH SUICIDE

— TOWARDS IMPROVED CARE AND RESTORED PSYCHOLOGICAL HEALTH

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To parents that have lost a child through suicide
and the persons who want to ease their pain

ABSTRACT

Background Parents that have lost a son or daughter through suicide are at risk of developing psychological morbidity that may become long-lasting and even life-threatening. Despite this the aftermath of a suicidal loss is yet to be carefully studied. One reason for the lack of studies is that trauma-related surveys may be hindered when the risks of asking participants are overestimated and the benefits not considered. Another reason is methodological difficulties. The goal of our studies is to provide knowledge that may be used to improve the professional care of suicide-bereaved parents. This thesis describes the first steps towards the goal.

Methods We developed hypotheses, questionnaires and an ethical protocol in a qualitative preparatory study with 46 suicide-bereaved parents (**paper I**). In a population-based survey we then collected data from parents who lost a child (15 to 30 years of age) to suicide, two to five years earlier. In all, 666 of 915 (73%) bereaved and 508 of 666 (74%) non-bereaved (matched 2:1) parents participated.

Results We found that 633 (95%) of the bereaved parents thought the study was valuable and that 604 (91%) would recommend another parent to participate. Among the bereaved 334 (50%) reported being positively affected by their participation, whereas 70 (11%) reported being temporary negatively affected (most referring to sadness). The bereaved parents' need for sharing their experiences regarding the suicide of their child was widely expressed and 639 (96%) thought the healthcare should contact parents bereaved through suicide to offer information and support (**paper II**). In all, 167 (25%) of the bereaved parents were currently taking antidepressants or were moderate-to severely depressed according to PHQ-9 versus 35 (9%) of the non-bereaved (RR 2.7). Fourteen percent of the bereaved reported they had had psychological morbidity more than 10 years earlier, versus 14% among the non-bereaved (RR 1.0). The highest levels of current psychological morbidity were found among the group of bereaved parents with psychological premorbidity **(paper III)**. Of the bereaved parents 460 had (69%) viewed the body at a formal setting, among these parents 430 of 446 (96%) answered "no" to the question "Do you regret that you viewed your child after the death". Among the parents that had not viewed 99 of 159 (62%) answered "no" to the question "Do you wish that you had viewed your child after the death" (**paper IV**).

Conclusions We found that most parents perceived the research participation as something positive and that the contact was welcomed. Bereavement was associated with high prevalence of psychological morbidity two to five years after the loss. We found no difference in prevalence of premorbidity between the bereaved and the non-bereaved parents. The significant minority that had premorbidity before the loss did however report the highest levels of current psychological morbidity. By and large everyone that had viewed their deceased child in a formal setting did not regret the viewing. Of equal importance, more than half of those who did not view the body did not wish that they had.

LIST OF PUBLICATIONS

This thesis is based on the following publications, which are referred to by their Roman numerals:

I. **Pernilla Omerov,** Gunnar Steineck, Bo Runeson, Anna Christensson, Ulrika Kreicbergs, Rossana Pettersén, Birgitta Rubenson, Johanna Skoogh, Ingela Rådestad, Ullakarin Nyberg. Preparatory Studies to a Population-Based Survey of Suicide-Bereaved Parents in Sweden. Crisis 2013;34:200-10.

II. **Pernilla Omerov,** Gunnar Steineck, Kari Dyregrov, Bo Runeson, Ullakarin Nyberg. The ethics of doing nothing. Suicide-bereavement and research: ethical and methodological considerations. Psychological medicine 2013;19:1-12.

III. **Pernilla Omerov,** Gunnar Steineck, Tommy Nyberg, Bo Runeson, Ullakarin Nyberg. Psychological morbidity among suicide-bereaved and non-bereaved parents: a nationwide population survey. BMJ open 2013:3(8):e003108.

IV. **Pernilla Omerov,** Gunnar Steineck, Tommy Nyberg, Bo Runeson, Ullakarin Nyberg. Viewing the Body after Bereavement due to Suicide. A Population-Based Survey in Sweden. Submitted.

CONTENTS

DEFINITIONS AND ABBREVIATIONS

(AUDIT) The Alcohol Use Disorders Identification Test.

Bereavement An acute state of intense psychological sadness and suffering experienced after the tragic loss of a loved one or some priceless possession.

(DSM IV) The American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders.

Formal setting In paper IV, formal setting refers to: “Emergency department or ward”, “Hospital church”, “Department of forensic medicine” or the “Funeral parlour”.

(ICD) International Classification of Diseases of the World Health Organization.

Non-bereaved parents Parents that have not lost a son or daughter through suicide or any other cause of death. The parents might (like the suicide-bereaved parents) have lost someone else (but not a child).

Odds Ratio (OR) Ratio of two odds.

(PHQ-9) The 9-item depression scale from The Patient Health Questionnaire.

Postvention* An intervention conducted after a suicide. Suicidology includes: intervention, prevention and postvention. The term was created by Ed Shneidman who also pointed out that postvention is prevention.

Relative Risk (RR) The ratio of the risk of disease among those exposed to a risk factor to the risk among those not exposed.

Risk factor A characteristic statistically associated with, although not necessarily causally related to, an increased risk of morbidity or mortality.

(SPES) Riksförbundet för SuicidPrevention och Efterlevandes Stöd.

Suicide The act of taking one's own life.

Suicide-bereaved parents Parents that have lost a son or daughter through suicide.

Unnatural death A death caused by external causes—e.g. injury or poisoning which includes death due to intentional injury, such as homicide or suicide, and death caused by unintentional injury in an accidental manner.

The definition of “postvention” was retrieved from: Shneidman, E. S. (1999). “Postvention: The Care of the Bereaved.” In A. Leenaars (Ed.), Lives and Deaths: Selections from the Works of Edwin S. Shneidman (pp. 444-456), Brunner/Mazel: Philadelphia, PA. The other definitions were retrieved of from Stedman’s medical lexicon, via WordFinder, Karolinska Institute 25/11/2013.

1 INTRODUCTION

My first encounters with suicide and bereavement were at the bedside in the intensive care unit. I was 17 years old and worked as a staff nurse. I remember that I was terrified of doing something wrong, not when handling life-supporting apparatus, but when meeting (or rather avoiding meeting) the patient who had just woken up from a suicide-attempt or when meeting shocked or grief-stricken family members. What if I said or did something that would deepen their pain? The care of suicidal patients later became my specialization in nursing and the focus of the first research projects that I was involved in (supervised and encouraged by Bo Runeson and Sonia Nilsson).

Norra Stockholms Psykiatri and former head of department professor Anna Åberg Wistedt gave me the opportunity to combine care-development with clinical work. Working night-time in the psychiatric emergency ward meant frequent (and sometimes challenging) encounters with suicidal patients, relatives and bereaved persons. When I met Ullakarin Nyberg, we had both thought about several ways to improve the clinical care we could offer. Ullakarin told me about the bereavement research done by Gunnar Steineck and his co-workers at the department of Clinical Cancer Epidemiology and suggested that we should apply these methods to suicide-bereavement. That was the start of this project and my PhD-journey.

Ilpo Okkola: En ensam själ som inte finner sin plats i det moderna samhället/ A lonely soul who cannot find his place in the modern society

2 BACKGROUND

> *”No one that has not been fighting to the breaking point can understand. This I tell you – I’ve done. For my beloved child. Who was torn between hope and despair, and who felt powerless and left out... And when life is shattered and everything becomes a black hole, then it is of critical importance that someone is there with the ability to help ease the fall”*
>
> *A mother who lost her daughter through suicide*

Losing your child must be one of the most painful experiences that can happen to a human being. The bereaved parent’s life is forever altered and will never be the same again. The world stops and at the same time life goes on (even if it might seem unbearable at times). Despite this, most parents manage to return to an everyday life where they are not overwhelmed and hindered by the loss[1]. For others the grief turns into psychological morbidity that may become long-lasting and even life-threatening[2-9]. It is therefore critical to identify those parents who are likely to suffer from the more severe consequences of the loss[10].

Complicated grief and long-term psychological morbidity such as depression and anxiety are common in the aftermath of a suicide loss[2,3,5,11]. Despite this, suicide-bereaved individuals’ need for professional help is yet to be carefully studied[1]. Today, the quality of professional help after a suicide-loss largely depends on chance rather than evidence-based guidelines. Existing register and qualitative studies provide valuable information, but need to be complemented by population-based surveys and intervention studies. Despite the potential, population-based surveys are rarely used in suicide postvention. One explanation for this is that bereaved populations often are considered as too vulnerable to approach and ethical committees might be reluctant to approve studies where the informants are personally involved[12-15]. Other explanations are the probable methodological challenges involved, for example how to achieve response rates high enough to provide adequate data[16].

We developed our study from a method that has been used in several bereavement-related studies at the Division of Clinical Cancer Epidemiology in Sweden[17-21]. The method starts with gathering bereaved individuals’ experiences and continues with a population-based survey where the experiences are quantified.

2.1 Ethical considerations

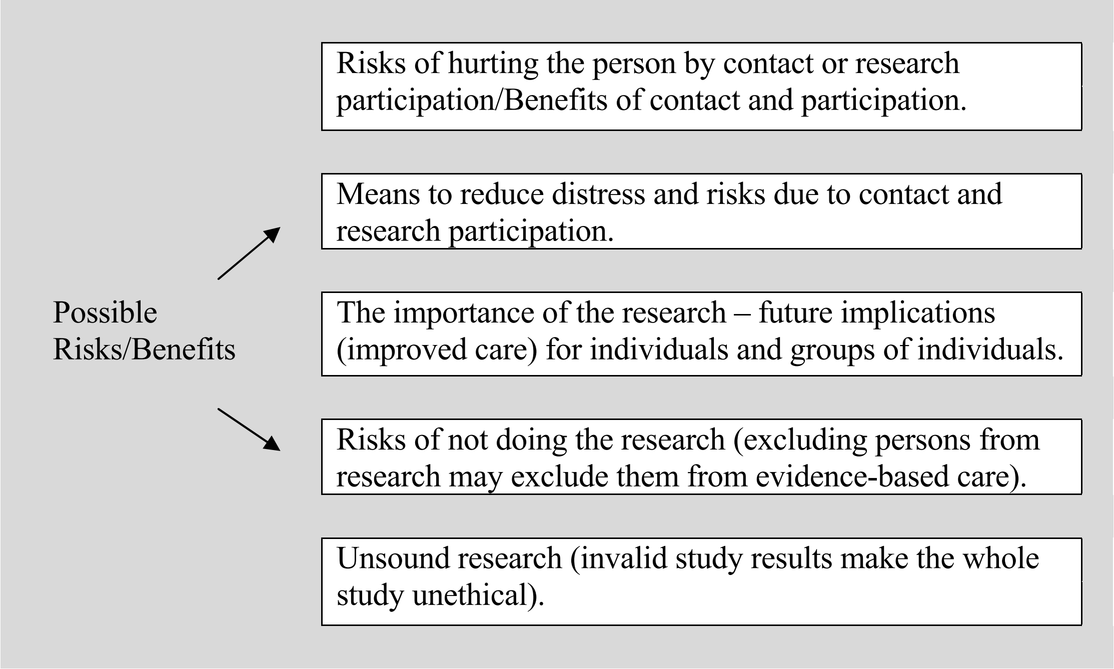


Figure 1. Ethical considerations: Contact and research participation in interviews and surveys

Regulations and institutions have been created to guide medical researchers in doing ethically sound research[22]. When doing research that includes human beings, one must always carefully consider that contact and participation might cause negative effects that can be harmful for the participants. One must also consider how to prevent and reduce these negative effects as well as how to handle them if they occur[22]. Compilations of trauma-related studies suggest that a minority of participants become distressed when being interviewed or when filling out a questionnaire but that the distress quickly diminishes[14,15,23-28]. Dyregrov and co-workers[26] performed a survey that included 262 parents who had lost a child to suicide, Sudden Infant Death Syndrome [SIDS] or an accident between 1997 and 1998. The survey focused on psychosocial health and support and the same issues were later investigated by in-depth interviews with 69 of the surveyed parents. Four weeks after the interviews, 64 of the parents answered a questionnaire about their experiences of being interviewed. All parents, even the ones who expressed the most distress and pain during the interviews, evaluated their participation as positive.

Runeson & Beskow[23] explored suicide-bereaved family members` (n=58) reactions to research participation (psychological autopsy interview) two weeks after their participation. During the telephone follow-up, none reported feeling worse than before the interview, 57% reported feeling better than before the interview and 83% reported feeling better than directly after the interview. Findings from previous studies suggest that recalling a traumatic event by telling or writing about it or by answering questions might raise the level of short-term distress but that re-traumatization or long-term harm are unlikely. Temporary distress must, however, be acknowledged and authors of several studies including suicide-bereaved persons have presented guidelines for reducing distress during contact and research[12-15,23,26,29]. In planning our study, we carefully considered these guidelines. For example, we contacted all parents by an introductory letter and followed up the information as well as queries or negative reactions by a phone call[13,26]. To be able to do so was one of the reasons why we chose the inclusion criteria having a listed address and telephone number as well as the need for understanding Swedish. We did not want to send letters with sensitive information if we were not sure about the address. We also wanted to make sure the parents understood the information and could give informed consent. The invasion of privacy and breaches of confidentiality must be considered in all research, since disrespect might lead to feelings of lost control and disgrace, as well as social stigma and family conflicts[22]. This might be especially important when it comes to suicide. Implying that the death of the child is due to suicide can be upsetting and shocking for some family members, especially in cultures where suicide might be especially stigmatised. This was the reason why we only included deaths categorised as suicides and not the uncertain deaths, even if the majority of uncertain deaths are due to suicide (for further details see method- and results section in the thesis and paper II).

After considering possible negative effects of research participation one must also consider the benefits and the necessity of the research. The benefits may be related to the contact or the participation in itself. For example, individuals needing professional help might be assisted to find appropriate help during the contact and participation might lead to greater understanding and satisfaction in helping others[26]. One must also consider the new knowledge that the research is designed to yield. More harshly put; excluding individuals from research might also mean excluding them from receiving evidence-based care, if the knowledge cannot be retrieved otherwise. Excluding individuals from research participation might be seen as unethical when we consider the possible benefits of the research, yet ethical reasons (direct or indirect) are often the reasons for the exclusions. For example it is essential that the individuals can choose freely whether to participate in the research and that their decision on participation is based on adequate understanding of what the research entails[22]. Traumatised individuals are sometimes believed to be too vulnerable for contact and for being able to give informed consent for research participation[14,15,28].

Research that is not methodically valid is unethical in itself. Firstly, it exposes the research participants to possible distress and risks without providing the promised knowledge. Secondly, implication based on invalid research results might be harmful rather than helpful[22] — for some individuals, for groups of individuals or for all individuals. We often had to consider both ethical and methodological reasons when deciding upon our inclusion criteria. The follow-up phone calls, for example, were important not only for providing support but also for receiving a high enough response rate (necessary for valid data).

2.2 Bereavement

2.2.1 Grief

While bereavement refers to the state of loss, grief is the natural response to loss[30]. Although every person grieves differently, there are similarities when groups of bereaved individuals are studied[1,31]. During the last century several theoretical perspectives and models of grief (stages, phases and processes) have been developed and presented[30,32-36]. The sudden death of a loved one often causes an acute sense of shock, disbelief, intensive pain, and, emotional numbness[1,31,37]. The initial shock is often followed by a reaction phase characterised by separation anxiety with yearning for the deceased, protest against the surrounding world and anxiety-ridden pain where suicidal ideation is common[1,31,37-39]. The separation anxiety can be followed by melancholy and despair. Gradually, disorganisation and resignation give way to reorientation where the bereaved person finds a way to live with the loss. During this phase, the lost person may be more or less included as a memory[31,37-40]. Although several grief-models present consecutive "stages or phases", most researchers today acknowledge that grief responses oscillate and that they can present themselves in different orders and numbers[41]. Despite grief related difficulties, previous research suggests that bereaved persons generally adapt to the loss without long-term morbidity[1]. Most bereavement-related studies however, were performed on spouses. Less is known about parents', childrens' and siblings' grief although some studies suggest that the death of a child might be especially difficult to endure[1].

Edvard Munch: Løsrivelse/Separation,1896. © Munch Museum/Munch—Ellingsen Group/BONO,Oslo 2013

2.2.2 Losing a child

Losing a child, regardless of its age, is a heart-breaking experience. In one blow the parent's world as they know it falls apart. Janoff-Bulman[42] writes that people tend to protect themselves against traumas like death and suffering by thinking that bad things only happen to others and that the painful insight when the worst does happen, may shake our "assumptive world" [42,12,13]**.** In the article "Loss of the assumptive world- How we deal with death and loss", 2005, p. 258 . Joan Beber[43] use the following definition:

> *"The assumptive world is an organised schema reflecting all that a person assumes to be true about the world and the self on the basis of previous experiences; it refers to the assumptions, or beliefs, that ground, secure, and orient people, that give a sense of reality, meaning, or purpose to life".*

In addition to the immense grief of losing a child – the loss is often accompanied with secondary losses. Losing an offspring may also mean losing hopes and dreams that will never be experienced or fulfilled[44]. Parents that lost an only child also may lose their identity as parents. Children are supposed to outlive their parents and when the child dies first it might give rise to survival guilt[45]. The parents also may struggle with feelings of guilt for having failed to prevent the death[46]. Strained relationships and ambivalent feelings for example between a parent and a teenager may result in feelings of anger, shame and guilt after the death[47].

Edvard Munch: Pubertet/Puberty, 1894–95. © Munch Museum/Munch—Ellingsen Group/BONO,Oslo 2013

2.2.3 The course of grief

In 1929 Sigmund Freud, who had lost his own daughter nine years earlier, wrote a personal letter to his bereaved friend Ludwig Binswanger (Ernst L Freud[48] ed.1961 p. 386).

> *… Although we know that after such a loss the acute state of mourning will subside, we also know we shall remain inconsolable and will never find a substitute. No matter what may fill the gap, even if it be filled completely, it nevertheless remains something else. And actually this is how it should be. It is the only way of perpetuating that love which we do not want to relinquish…*

The grief over the lost child may never go away completely. However, although the frequency and intensity of grief may fluctuate (for example during anniversaries), bereaved people often say that the painful grief-responses subside with the passing years[31]. The grieving response is affected by many factors, including personality, coping style, culture, previous experiences, and the nature of the loss[1]. It is therefore difficult to say when the grief may be perceived as deviating from a normal course. In a longitudinal study including 173 parents that had lost a child or a teenager by suicide, accident or homicide, 70% of the parents said it took three to four years before they could get a perspective on the death and could start to live their lives again[49]. The same study showed, however, that signs of mental ill-health and trauma were 2 to 3 times more common in the bereaved parents compared to the normal population five years after the loss. In Kreicbergs and co-workers'[20] study of parents that had lost a child to cancer (n = 449), the bereaved parents showed elevated levels of anxiety and depression 4 to 6 years after the loss. Only 7 to 9 years after the loss their levels of anxiety and depression were comparable to those of a normal population.

Edvard Munch: Livets dans/Dance of Life, 1899–1900 © Munch Museum/Munch—Ellingsen Group/BONO,Oslo 2013

2.2.4 Bereaved by suicide

In addition to the grief over losing a child, different causes and modes of deaths may present different additional challenges. For example a sudden, traumatic, unexpected and untimely death is often thought of as a risk-factor for a complicated course of grief[1,5,31,50]. However long-term suffering and anticipation of an impending or threatening death may also be associated with difficulties that might affect the bereavement-outcome[1].

When someone dies by their own hand tormenting queries and underlying sentiments are often set in motion (by the survivors as well as by those around them). Parents that have lost a son or daughter through suicide often tell how they struggle to understand how this could happen. Previous studies show that feelings of guilt, self-blame, shame and isolation are common after a suicide loss[38,46,50,51]. Jordan[46] describes three particular themes:

- the search for meaning and an explanation of the death
- shame- and guilt feelings related to:
    blame for causing or triggering the suicidal-crisis
    failure in predicting or preventing the suicidal-crisis death
    the death being a suicide
- anger at being abandoned and rejected by the deceased (further augmented guilt-feelings)

In addition to the factors mentioned above, the grief-response may also be further complicated by the exposure to a traumatic event due to witnessing the suicidal act or discovering the dead body[52].

Examples of queries commonly found in the aftermath of a suicidal loss

Did my son or daughter understand what he or she did? That death is forever?

What was he or she escaping from? What preceded the suicide?

For how long had he or she been suffering? How deep was the suffering?

Could I have prevented the suffering and the death? What if I…

Did I do something that caused the suffering or triggered the death? What if I…

Why does this happen to me?

Figure 2. Examples of queries proposed by parents bereaved by suicide

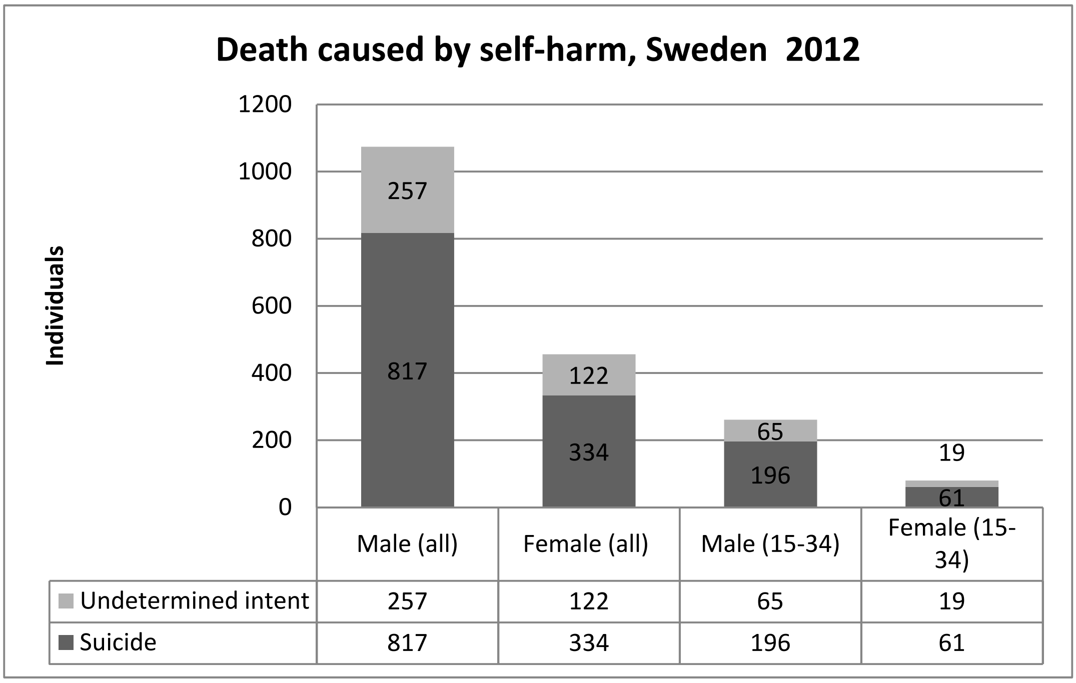
2.2.5 Suicide in general

2.2.5.1 Global perspective

Around one million individuals die through suicide in the world each year and the annual number of suicidal deaths is increasing, especially within the younger populations. Suicide is a prominent cause of death among men and women in both developing and developed countries. In 2013, World Health Organization stressed the elevated suicide rates as a global health threat[53]. In 2010 suicide accounted for about 5% of the global deaths among individuals aged 15 to 49 years[54] and suicide is ranked among the top ten leading causes of death among teenagers and young adults in most countries today[55]. According to the Institute for Health Metrics and Evaluation, death due to self-harm was one of the top three reasons for deaths in the age group between 15 to 49 years in EU and the British Commonwealth in 2010, except for in Greece where is was ranked as number seven. In Sweden, death due to self-harm is the number one death cause, both among men and women, in the ages from 15 to 49 years[54] (http://ihmeuw.org/m93). The suicide rates in Sweden are often said to be in the midrange in comparison with the rest of the world. However, comparisons across countries must be done with caution, since data is estimated from different sources and settings which may compromise their reliability as well as the comparability[54].

2.2.5.2 Suicide in Sweden

In Sweden, most deaths that occur among teenagers and young adults are due to injuries and around half of these deaths are ruled out as suicides. In the last fifteen years, the suicide rates have declined in all age groups except for the younger population[56]. In 2012, 1530 deaths were registered as due to self harm (including 379 events of undetermined intent). Of these 341 were between 15 and 34 years old.



	Male (all)	Female (all)	Male (15-34)	Female (15-34)
■ Undetermined intent	257	122	65	19
■ Suicide	817	334	196	61

Figure 3. Number of deaths due to Self-harm (suicide and self-harm with undetermined intent) in Sweden 2012. Data was retrived from The National Board of Health and Welfare (Socialstyrelsen) http://www.socialstyrelsen.se/statistik/statistikdatabas/dodsorsaker 201312/8/2013

2.3 Development of psychological morbidity

Overwhelming life-events as well as difficult life-situations can trigger the onset of depression and maintain or worsen an ongoing depression[57]. Several theories have been proposed to explain the mechanism between stress and ill-health. Lazarus and Folkman[58] suggest that stress might be thought of as a consequence when “pressure exceeds one's perceived ability to cope” which is also the definition of stress we use in this study. Our definition of “vulnerability” was based on deFur and co-workers’[59] suggestion that vulnerability is how “individuals or groups of individuals respond and recover from stressors inadequacy or not as well as the average”.

Using Zubin and Springs[60] stress-vulnerability model to explain the onset of depression,(figure 4) one may assume that every person has a degree of vulnerability that represents a threshold for his or her development of depression. Thus the threshold for triggering depression varies from one person to another. According to the theory a minor stressor may cause depression only in persons with high vulnerability. A major stressful event however, like a child’s suicide, may cause depression even in individuals’ with low vulnerability. There are also models that consider the degree of psychological morbidity. Using Ingram and co-workers model for “Cognitive vulnerability to depression”[61], the loss by suicide (major stressful event) may cause more severe depression among persons with previous psychological morbidity (higher vulnerability) and milder depression among persons without previous psychological morbidity (lower vulnerability)

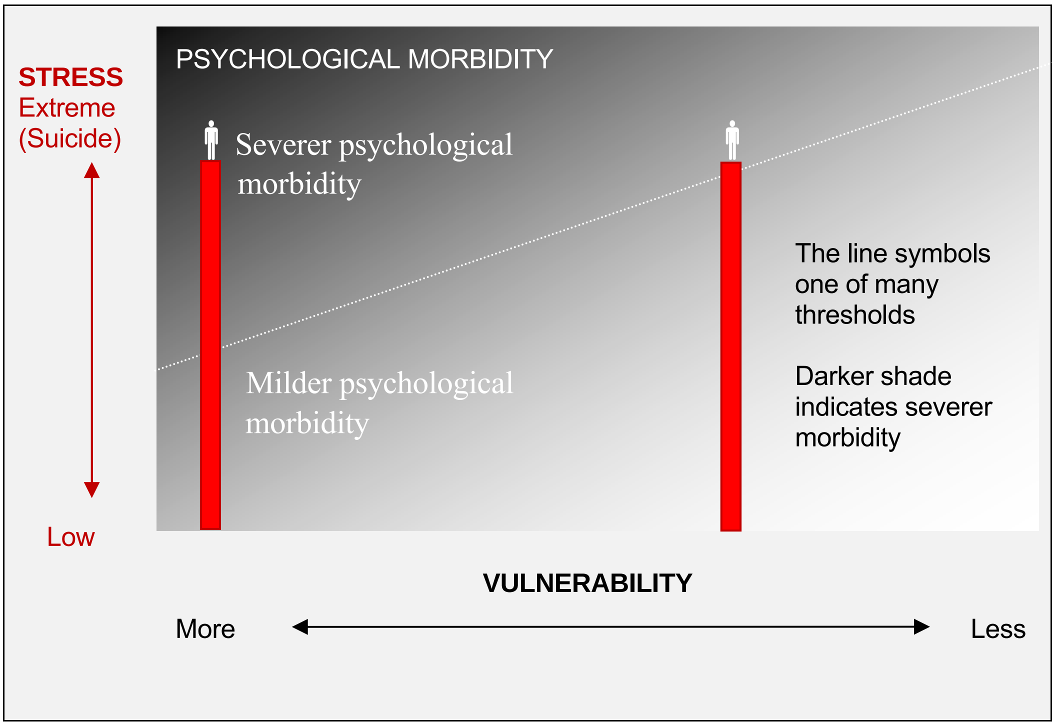


Figure 4. Stress-vulnerability model to explain the onset of grief-related depression in the aftermath of a suicide loss

2.4 Overview of risk factors

Previous studies have suggested risk factors that might be useful in identifying people who might benefit from professional help. Some factors are related to the loss, others to the bereaved individual and his or her environment[1,10,46,51,62-64]. The researchers Stroebe, Folkman, Hansson and Schut[10] present a number of factors in their model *"The integrative risk factor framework for the prediction of bereavement outcome"*(figure 5).

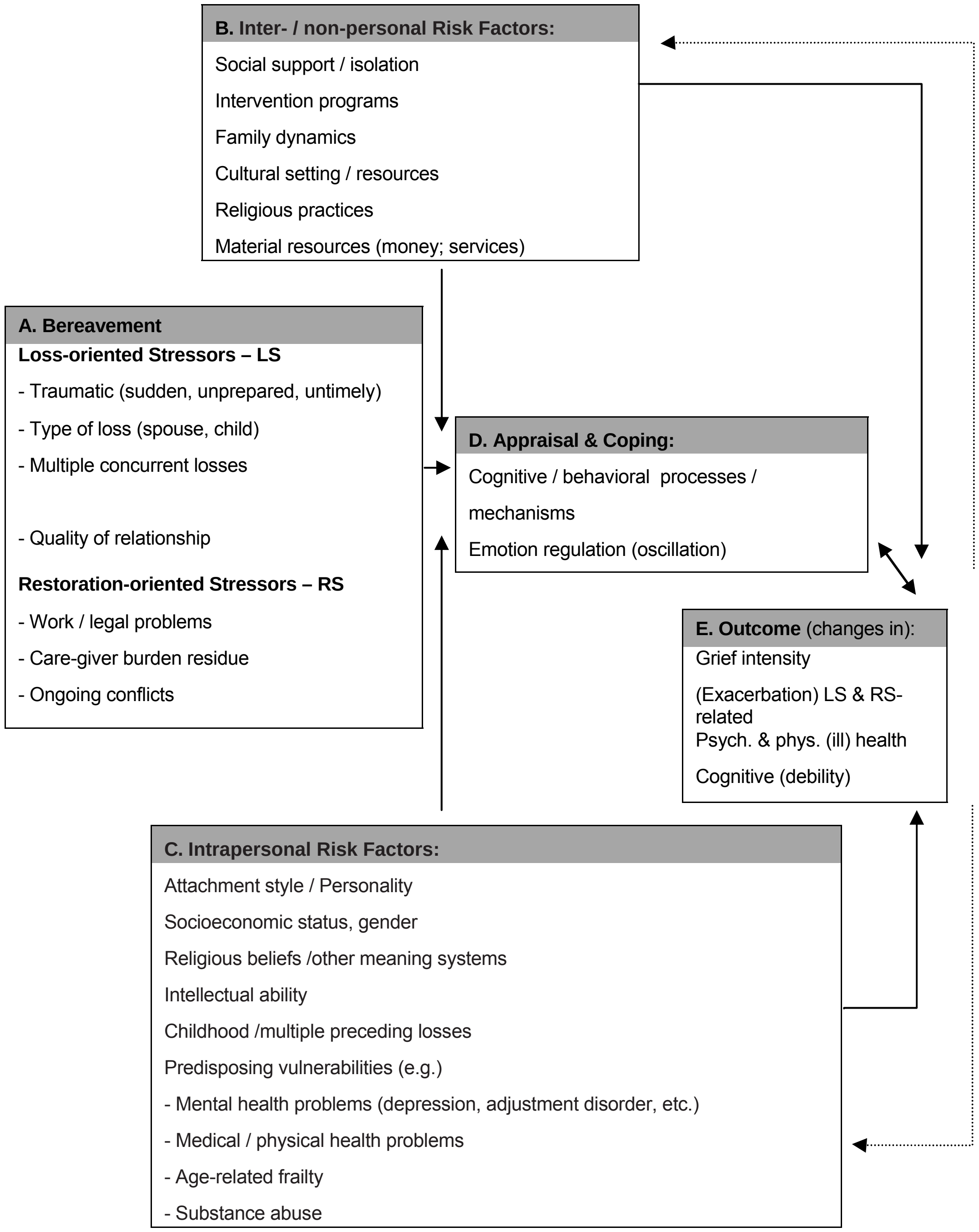


Figure 5. Based on Margaret Susan Stroebe, Susan Folkman, Robert O. Hansson, Henk Schut model "The integrative risk factor framework for the prediction of bereavement outcome" published in Soc Sci Med 2006;63(9)2440 –51. http://dx.doi.org/10.1016/j.socscimed.2006.06.012

2.5 Grief and psychiatric disorders

The death of a family member increases the risk of developing psychiatric disorders related to depression, anxiety and trauma/stress related disorders[2,4,65]. In addition, symptoms of grief and those of depression or anxiety overlap: Symptoms like “feelings of intense sadness, rumination about the loss, insomnia, poor appetite, and weight loss” may for example be present both in depressive disorders and during bereavement[66]. Researchers have pondered over how to distinguish normal grief response and clinical depression for a century. In one of the first significant writings on grief – *Mourning and Melancholia*, published (translated by Strachey[67],1999 p. 246) 1917 Sigmund Freud wrote:

> *“In mourning it is the world which has become poor and empty; in melancholia it is the ego itself.”*

In Sweden we often use the Diagnostic and Statistical Manual of Mental Disorders (DSM) to define psychiatric disorders[68]. In DSM-IV, the criteria for “Major Depressive Disorder” included a “bereavement exclusion” that was intended to exclude individuals that had experienced the death of a loved one during the last two months[68]. In DSM-5 this exclusion was removed. In this version bereavement is described as one among other responses to a significant loss that might incite or appear like a major depressive episode. The new criteria for Major depressive disorder also includes a note regarding bereavement and depression[66] (see table 1). The removal of the “bereavement exclusion” and its consequences for the bereaved are lively debated. One of the reasons for removing this exclusion is to prevent that major depression is being overlooked in bereaved individuals, thus hindering appropriate treatment with prolonged suffering as a result[69]. Another reason is that other stressors than bereavement, for example “being a victim of a physical assault or a major disaster”, also might resemble a major depression disorder[66]. On the other hand, criticism against removing the “bereavement criteria” includes that normal grief responses might be labelled as pathological as well as incorrectly treated with medication[69]. American Psychiatric Association, the developer of DSM, writes that the decision whether to diagnose a bereaved individual or not with depression “inevitably requires the exercise of clinical judgment based on the individual’s history and the cultural norms for the expression of distress in the context of loss”[66] (see table 1).

2.5.1 Depression after bereavement

Two longitudinal surveys found that while a history of depression is associated with recurrence of depression, one brief bereavement-related depressive episode is not[30,31]. In a sample from a longitudinal survey including the US general population[30], 865 of 43,093 participants with a lifetime history of one brief bereavement-related depressive episode reported major depression three years later. In comparison, 2,320 of 27,074 participants with no previous history of depression reported major depression at follow-up, resulting in a non-significant difference (RR 0.85; 95% CI 0.52 to 1.59). Similar results were found in Wakefield's longitudinal survey.[31]

There are also previous studies that show that parental bereavement is associated with an increased risk of first time depression. Li and co-workers[3] followed more than 1 million parents during 1970 to 1999 and found that parents who had lost a child, age six years or older, had a higher relative risk of being hospitalised for affective disorder; 2.72 (95% CI 1.54 to 4.81) among mothers and 1.85 (95% CI 0.59 to 5.75) among fathers. Kessing and co-workers performed a case-control study[2] on major life events and first-time admission for depression, which included 13,006 depressed patients and 260,108 age- and sex-matched controls. In this study, suicide of a family member was associated with 1.95 relative risk (95% CI 1.30 to 2.92) of being first-time admitted for depression, whereas death of a family member by causes other than suicide was associated with a non-significant relative risk of 1.11 (95% CI 0.91 to1.35).

Edvard Munch: Aften på Karl Johan/Evening on Karl Johan Street, 1892© Munch Museum/Munch—Ellingsen Group/BONO,Oslo 2013

Major Depressive disorder

Diagnostic Criteria

A. Five (or more) of the following symptoms have been present during the same 2-week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure.

1) Depressed mood most of the day, nearly every day, as indicated by either subjective report (e.g., feels sad, empty, hopeless) or observation made by others (e.g., appears tearful). (**Note:** In children and adolescents, can be irritable mood.)

2) Markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated by either subjective account or observation).

3) Significant weight loss when not dieting or weight gain (e.g., a change of more than 5% of body weight in a month), or decrease or increase in appetite nearly every day. (**Note:** In children, consider failure to make expected weight gain.)

4) Insomnia or hypersomnia nearly every day.

5) Psychomotor agitation or retardation nearly every day (observable by others, not merely subjective feelings of restlessness or being slowed down).

6) Fatigue or loss of energy nearly every day.

7) Feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self-reproach or guilt about being sick).

8) Diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as observed by others).

9) Recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide.

B. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.
C. The episode is not attributable to the physiological effects of a substance or to another medical condition.

Note: Criteria A–C represent a major depressive episode.

Note: Responses to a significant loss (e.g., bereavement, financial ruin, losses from a natural disaster, a serious medical illness or disability) may include the feelings of intense sadness, rumination about the loss, insomnia, poor appetite, and weight loss noted in Criterion A, which may resemble a depressive episode. Although such symptoms may be understandable or considered appropriate to the loss, the presence of a major depressive episode in addition to the normal response to a significant loss should also be carefully considered. This decision inevitably requires the exercise of clinical judgment based on the individual's history and the cultural norms for the expression of distress in the context of loss.

In distinguishing grief from a major depressive episode (MDE), it is useful to consider that in grief the predominant affect is feelings of emptiness and loss, while in MDE it is persistent depressed mood and the inability to anticipate happiness or pleasure. The dysphoria in grief is likely to decrease in intensity over days to weeks and occurs in waves, the so-called pangs of grief. These waves tend to be associated with thoughts or reminders of the deceased. The depressed mood of MDE is more persistent and not tied to specific thoughts or preoccupations. The pain of grief may be accompanied by positive emotions and humor that are uncharacteristic of the pervasive unhappiness and misery characteristic of MDE. The thought content associated with grief generally features a preoccupation with thoughts and memories of the deceased, rather than the self-critical or pessimistic ruminations seen in MDE. In grief, self-esteem is generally preserved, whereas in MDE feelings of worthlessness and self-loathing are common. If self-derogatory ideation is present in grief, it typically involves perceived failings vis-à-vis the deceased (e.g., not visiting frequently enough, not telling the deceased how much he or she was loved). If a bereaved individual thinks about death and dying, such thoughts are generally focused on the deceased and possibly about "joining" the deceased, whereas in MDE such thoughts are focused on ending one's own life because of feeling worthless, undeserving of life, or unable to cope with the pain of depression.

D. The occurrence of the major depressive episode is not better explained by schizoaffective disorder, schizophrenia, schizophreniform disorder, delusional disorder, or other specified and unspecified schizophrenia spectrum and other psychotic disorders.

E. There has never been a manic episode or a hypomanic episode.

Note: This exclusion does not apply if all of the manic-like or hypomanic-like episodes are substance-induced or are attributable to the physiological effects of another medical condition.

Reprinted with permission from the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, (Copyright ©2013). American Psychiatric Association.

Table 1. Major Depressive Disorder, Diagnostic criteria. The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5)

2.5.2 Psychological premorbidity

We found two population-based studies that investigated psychological premorbidity among suicide-bereaved and non-bereaved parents using registries on psychiatric admissions and diagnoses: Stenager and Qin`s study[15] on 4142 individuals aged 9–35 years who committed suicide in Denmark during the period 1981 to 1997 and Bolton and co-workers study[16] of 1415 suicide-bereaved parents in Manitoba, Canada between 1997 and 2007. Stenager and Qin[15] found that about 6% of the suicide-bereaved parents and about 3% of the non-bereaved controls had been admitted to a psychiatric hospital ten years prior to the suicide and about 1.1% of the suicide-bereaved and 0.5% of the non-bereaved had been admitted within the past three years. In Bolton and co-workers study[16], 28% of the suicide-bereaved parents had had a mental disorder two years prior to the suicide, according to the registers. Bolton and co-workers also showed that 15% of the suicide-bereaved parents had been diagnosed with depression two years prior to the suicide. In comparison, 11% of the control parents had been diagnosed with depression at that time. Two years after the suicide, the prevalence rose to 31% among the suicide-bereaved parents, while the control parents' prevalence barely changed (10%). The authors suggest that the suicide-bereaved parents have a premorbidity due to shared genetic and environmental factors as one part of the explanation, but also recognise that the parents might have stress-related psychopathology due to factors that preceded the suicide.

3 AIMS

The overall aim of our research is to improve the professional care of parents that have lost a son or daughter through suicide. This thesis describes the first steps towards this goal, beginning with developing an ethically and methodologically sound study design. We then continue with investigating psychological morbidity and some aspects of care that might be amenable to change.

The specific aims of the research on which the papers in the thesis are based were:

- To identify factors that might be of importance for long-term psychological morbidity in the aftermath of losing a child through suicide (hypotheses generating). And to create a questionnaire that assess these factors (Study I).
- To develop an ethically and methodologically sound research design and to evaluate how the bereaved and non-bereaved parents perceived the contact with responsible researchers as well as their participation in the study (Study II).
- To investigate prevalence of psychological morbidity (dated and current) among parents that have lost a child through suicide, two to five years earlier and among parents that have not lost a child (Study III).
- To assess how many among those that viewed the body of the dead child in a formal setting that regretted the experience, and to investigate if viewing the body is associated with lower levels of psychological morbidity two to five years after the loss (Study IV).

3.1 Conceptual framework

Our study design follows the method developed at the Division of Clinical Cancer Epidemiology[17-21]. This method includes a qualitative preparatory study and an epidemiological main study guided by the hierarchical step-model (further discussed in the methods section). The overall aim of our study is to restore psychological health in the aftermath of a suicide-loss. We therefore focus on vulnerability, and negative stress rather than resilience and the grief process. When creating our hypotheses we used the conceptual frameworks below to divide factors into possible exposures and outcomes as well as factors that might increase the vulnerability. The figure is based on stress-vulnerability and cognitive stress-process perspectives[10,58-60,70] described earlier. The figure shows our model of how the suicide loss of a child (exposure) may affect the level of psychological morbidity (outcome) in bereaved parents. In the model we also present factors (individual and environmental) that might increase the individual's vulnerability for the outcome. The life arrow (in the figure) emphasises that the loss occurs in an on-going life with a past, a present and a future. In accordance with previous models[10,59], our framework suggests that factors related to the bereaved individual as well as to the personal environment affect the responses to and recovery from the loss.

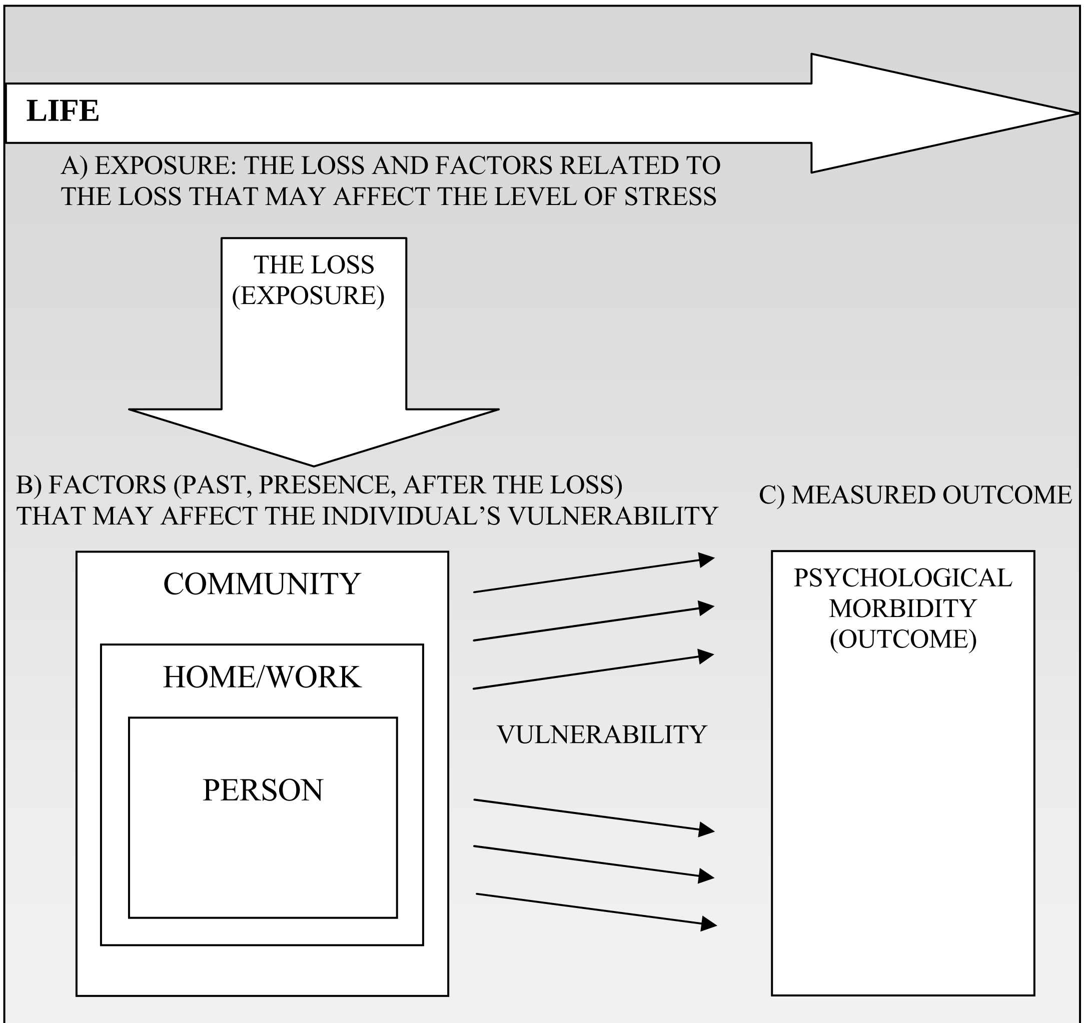


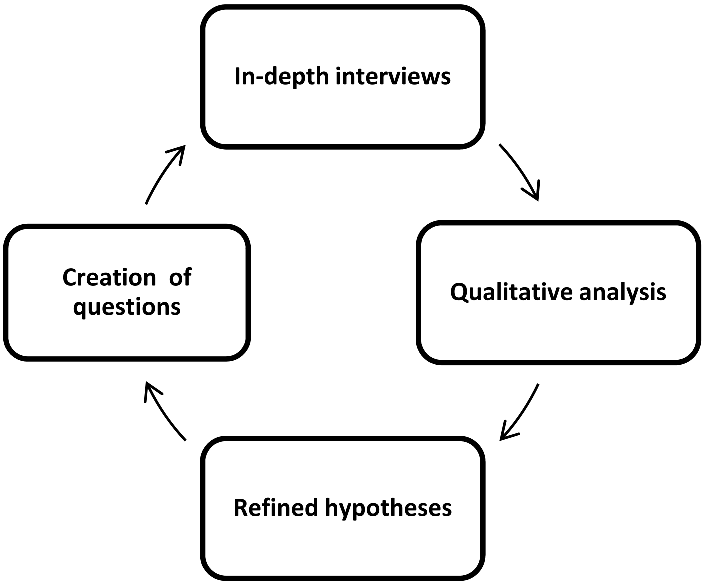
Figure 6. Conceptual model for considering how the suicide loss of a son or daughter (exposure) may affect the level of psychological morbidity (outcome) in bereaved parents and factors (individual and environmental) that may increase the individual's vulnerability for the outcome.

3.2 Preparatory study (Paper I)

The aim of the preparatory study was to develop hypotheses, questionnaires and an ethical protocol for our population-based survey. The preparatory study can be divided into three phases: 1) development of hypotheses and the questionnaire 2) testing the questionnaire 3) pilot study.

3.2.1 Development of hypotheses

We started the study with loosely formed hypotheses on what we believed to be helpful for the bereaved parents in the wake of a suicidal loss. We based our beliefs on findings from previous research within the field, clinical experiences and encounters with external experts as well as bereaved individuals. In-depth interviews and qualitative content analysis was thereafter used to refine our hypotheses (define exposures, outcomes, confounders and effect modifiers) and to cover them with questions.



3.2.2 In-depth interviews

Informants

We identified informants through: the Swedish suicide survivors group (SPES) (n=9), a psychiatric clinic in Stockholm (n=9), an external expert in suicidologi (n=4) and advertisement (n=1) by means of purposive sampling. In all, 17 parents agreed to being interviewed, the youngest was 51 years old and the oldest was 78 (table 2). Three mothers were divorced and lived alone, while the rest lived together with the bereaved father (all parents were interviewed individually). One couple had adopted their child. The parents had various experiences of their child's psychological distress ranging from no visible problems to evident symptoms, including diagnosed psychiatric disorders with several prior suicide attempts. We left it to the informants to decide upon where and when to meet for the interviews; four interviews took place at the hospital and 13 in the parent's home[26]. Six parents declined to be interviewed; one person gave no reason and five (all identified through the medical records) expressed disappointment with their child's health-care.

Interview	Informant	Residence at time of interview	Years since loss	Sex of the lost child	Age of the lost child	Child living with parent
1	Mother	Town	4	Son	20	No
2	Father					
3	Mother	Countryside	3	Son	26	No
4	Father					
5	Mother	Large town	2	Daughter	20	Yes
6	Mother	Town	5	Son	22	No
7	Father					
8	Mother	Countryside	5	Son	23	No
9	Mother	Large town	3	Son	21	Yes
10	Mother	Large town	2	Son	26	No
11	Father					
12	Mother	Large town	6	Daughter	20	No
13	Mother	Large town	2	Daughter	21	No
14	Mother	Countryside	-	Daughter	26	No
15	Father					
16	Mother	Town	-	Son	16	Yes
17	Father			Son	-	No

Table 2. In-depth interviews with parents who have lost a son or daughter through suicide. All 17 interviews were done separately by me.

Introductory letter

We contacted the parents by an introductory letter. In this letter we emphasised that participation was voluntary and informed about the possibility to end participation at any time without further explanation. Our names and telephone numbers were listed and the parents were encouraged to contact us if they had any questions or if they needed support at any time during the study[22]. In the introductory letter we wrote that the aim of the study was to improve our knowledge about suicide-bereaved parents' health and needs in the aftermath of their loss. We also wrote that the information would be used to improve the professional care provided for a parent that had lost a son or daughter to suicide. We explained to the parent that the interview might be emotionally challenging by informing that we intended to ask about the circumstances around the son's or daughter's death[22,26]. In order not to miss any details we also included that we wanted to record the interviews.

In-depth interviews

I was usually invited to the parents' home to spend the whole day learning about the family's experience (reading letters, seeing pictures, and visiting important places). Before the interview started, the interviewer reminded the parent about their right to end their participation at any time[22]. All interviews started with the question: *"Can you tell me about your son or daughter?"* Most parents told their story as a narrative: they began by describing the child and the events that built up to a change, the first suicide attempt or the suicide, and the time after the suicide when the parent tried to make sense of life again. All informants consented to be recorded and the recordings were later used by the interviewer to recapitulate what had been said. The interviews were verbatim transcribed and returned to the informants for comments before being included in the qualitative analyses. No changes were made but some informants added extra information. The informants received both written and verbal information about how the interview material was to be used (in peer-review articles and other publications as well as for educational purposes) and all consented. The verbal consent was later complemented with a written one. Our interviews provided rich data that will be analysed from different angles (will be presented in future papers). In this thesis we only describe how we used the interviews to create and test our questionnaire (see validation phase).

3.2.3 Qualitative analysis

The aim of the qualitative content analysis was to see if the informants brought up new areas of concern for our study (not yet covered by our working hypotheses) and to use the informants' own wordings to create specific questions. We discussed underlying meanings, possible interpretations and theories during the analysis but did not work on formulating themes since our goal, at this stage, was to create a questionnaire with concrete questions that were close to the informants own wordings.

1. Each interview was verbatim transcribed by a research secretary and re-read by the interviewer **(unit of analysis).**

2. The whole transcription was thereafter divided into quotations **(meaning units)** labelled with a descriptive code using the software OpenCode[71].

3. The meaning units were copied to a separate document and sorted into categories **(abstraction).** Long quotations were shortened (**condensation).**

4. By the use of OpenCode, we could move between whole transcripts and quotes from different interviews (with the same code).We could also easily overlook existing codes/categories to see when the need for new codes ceased **(saturation).**

Figure 7. Our qualitative sorting was inspired by Graneheim & Lundman[72] To sort and classify our data we used OpenCode, developed by University of Umeå (http://opencode.software.informer.com/).

We continuously sorted the condensed meaning units into the questionnaire draft and turned them into categories, sub-categories and questions. When the need for new codes ceased we interviewed three more informants and no more codes (of interest for our research) were raised by further interviewing. After 17 interviews the questionnaire consisted of 306 questions, divided into three (the broadest) categories:

The time before death (from the child’s birth until the death)
This was the category most strongly emphasised by the informants. Several parents were eager to describe their child as a person and told stories about his or her upbringing. Several quotes also referred to disappointment with their child’s school or contact with the healthcare system.

The death (from finding out about the death until the funeral)
This category generated fewer quotations. Most concerned encounters with professionals such as the police or the ambulance crew saying or doing something that the parents perceived as positive or negative. Despite the brevity of the parents’ accounts of this phase, we created many questions for this section since detailed information may be important for our hypotheses.

The time after death (from the funeral until the day for the interview)
This category generated the least number of quotations. Information about a perceived lack of professional support and about the importance of support groups for suicide survivors dominated this category.

3.2.4 Creating questions and questionnaires

We formulated each question to measure one conceptual entity and to be answered by one response alternative[73,74]. When we chose sets of response alternatives we considered those that had been tested in previous studies within our research group[75-77]. In the preparatory study, we found that the response sets in the examples below were the easiest to understand and we therefore used them frequently throughout the questionnaire. As in these examples, we often encouraged the informants to complement their answers by writing a personal note.

Have you taken medication against anxiety during the preceding month?

☐ No
☐ Yes, occasionally
☐ Yes, 1-3 days per week
☐ Yes, 4-5 days per week
☐ Yes, 6-7 days per week

If yes, which or what medication have you taken against anxiety during the preceding month:

____
____

Do you regret participating in this study?

☐ No
☐ Yes, a little
☐ Yes, moderately
☐ Yes, much

Please let us know why:

____
____
____
____

Have you thought about your child during the preceding year?

☐ No
☐ Yes, but not every month
☐ Yes, at least every month
☐ Yes, at least every week
☐ Yes, every day

Please tell us about your thoughts:

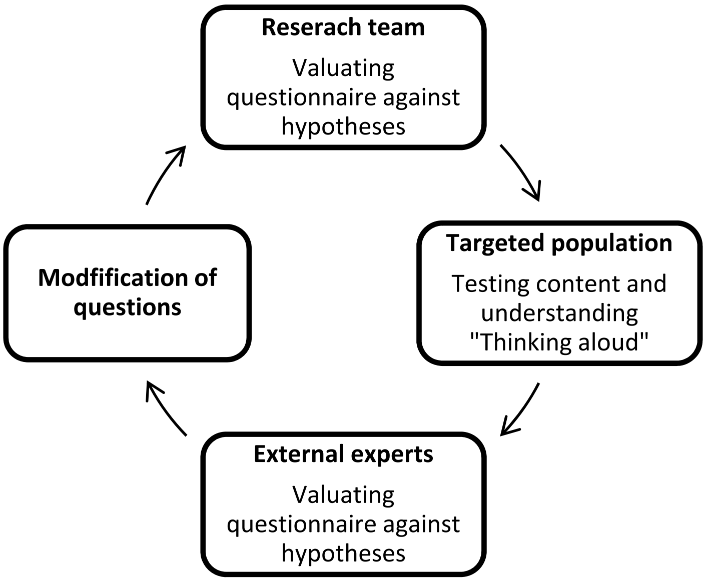
____
____
____
____

3.2.4.1 *Order of the questions*

Questionnaires are often designed chronologically, beginning questions concerning the time before the problem, continuing with questions about the problem and ending with questions concerning the respondent' current status. However, preceding questions can affect the answers to subsequent ones[78]. Hauksdóttir and co-workers[78] investigated if the order of questions affected the self-assessed rating of psychological morbidity among 76 men who had lost their wife through cancer four to five years earlier. The widowers were randomly allocated to one of two questionnaires with the same content but with different placement of the questions measuring current well-being. The results showed that respondents that answered the questions regarding current well-being after answering the questions concerning their wife's disease and death rated the highest prevalence of psychological morbidity. Self-rated anxiety and depression were the measures most affected by the order of the questions. In our preparatory study we observed elevated anxiety and lower mood when the informants described the child's suffering and death. We therefore placed the questions regarding the respondents' current well-being at the beginning of the questionnaire (figure 9).

3.2.4.2 *Testing the questionnaire*

We used validated psychometric scales for our main outcomes anxiety and depression, but for most factors related to the parents' experiences we had to develop study-specific questions. We tested the questions in the preparatory study as well as in the analysis phase after the data collection (see discussion).



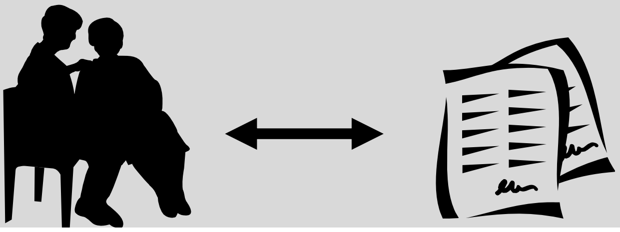
3.2.4.3 Content and understanding

To answer our hypotheses, the questionnaire had to cover a wide range of domains and factors. To ensure that we had not forgotten anything essential we asked external experts to view both the hypotheses and the questionnaire draft. These experts were other researchers and clinicians working with suicide prevention and postvention, as well as suicide-bereaved individuals. We also asked the parents who were involved in the preparatory study (n=47) whether they thought that the important issues regarding their loss had been covered in the questionnaire[72]. The question-answering process is a cognitive process that not only requires that the respondents must comprehend the question as intended but also that he or she must be able to answer the questions correctly. This entails retrieving the necessary information from memory, making a judgement about the information needed to answer the question, and finding a suitable response alternative[79]. Inspired by methods sometimes described as “thinking aloud” we investigated how the respondents understood the questions and whether they could (and wanted to) answer them accurately. In all, 46 suicide-bereaved parents were involved in this process; 17 had already been interviewed and 29 were new to the study (see pilot study below). All validation interviews and contacts during the process, as well as the in-depth interviews, were carried out by me.

The interviews began by me asking the respondent to answer the questionnaire and to voice whatever thoughts that came up when answering each question[79]. We soon discovered that this approach was too energy and time-consuming for the three respondents that participated. They raised a lot of comments in the beginning but the comments ceased as their energy declined. We therefore decided to modify the testing. After that I asked the parents (n=43) to answer the questionnaire draft alone and to comment on questions that they found difficult to answer or negative in any other way. Some respondents called me to discuss their queries several times during the answering process, while others commented on everything during one telephone call. I also called the informants to discuss multiple, missing or confusing answers in their completed questionnaires. After that I compared the information from the in-depth interviews (n=17) with the answers from the questionnaires (n=17) and discussed incongruent information with the respondents. We discussed questions that were perceived as difficult by more than one parent within the research group considering importance for the hypotheses, since we needed to reduce items, and how the questions could be modified.

- Comparing the information from the interviews (n=17) with information from the questionnaires (n=17) and discussing incongruent findings.

- Discussing the queries and multiple, missing or confusing answers in the completed questionnaires with the respondents (n=47).



3.2.4.4 Modification of the questionnaire

We found that we had covered most areas of interest in our working hypotheses and therefore we only added a few new questions after the qualitative content analysis. One of the questions we added was*: "Do you feel ashamed over your son's or daughter's suicide?"* Several parents commented on the lack of questions regarding the siblings. We dealt with this response by including these questions in an ongoing study about the loss of a sibling to suicide. Several participants found the questionnaire too voluminous, and commented on some questions being similar or irrelevant. We therefore reduced the 306 main questions (to be answered by everyone) to 196 with follow-up questions and fields for free comments.
Two sets of study-specific questions were considered difficult to answer by several informants; one set included personality traits and the other primary emotions. We chose to omit these questions since we found it difficult to create valid questions (we had already ruled out using validated inventories since they were all too extensive). There were also some questions that were considered strange by a few informants that we chose to keep since they were important for the hypotheses and for comparisons across questions. One example was the question: "*When was the first time you could experience happiness after the loss?"* Some parents wrote that they assumed that no one could feel happiness after such a loss. There were also several informants that pointed out that the second item in the scale for measuring hazardous alcohol consumption (AUDIT) *"How many drinks containing alcohol do you have on a typical day when you are drinking?"* response set *"1-2", "3-4", "5-6", "7-8",* and *"more than 10"* lacked a suitable response for persons who did not drink alcohol. Despite this we kept the inventory as it was (see statistical analyses).

We also modified some questions, for example the question: *"How did your child take his or her life?"* One mother stated during the interview that her daughter died by taking an overdose of antidepressant drugs, while she did not answer this question in the questionnaire. When confronted with this discrepancy she told us that she did not want her daughter's death to be associated with illegal drugs and therefore had avoided the answer alternative *"Poisoning with, e.g., drugs or medication."* Accordingly, we changed it to *"Poisoning with, e.g., medication, chemicals or some kind of gas"*. The alternative *"Some kind of gas"* was merged with *"Poisoning"* after a comment that *"some kind of gas"* and *"poisoning* "could be synonymous. A father stated that he received the death notice from a physician but in the questionnaire he answered *"no"* to the question: *"Did you receive the death notice by a professional person"*. When we asked about the divergent answers he told us that he did not think that the physician acted in a professional way. We could not find a better way to phrase this question, instead we added an information box with the text: *"The word "professional" means a person on duty for example a policeman or a physician and does not refer to the person's suitability or competence"* next to the question.

Two mothers had different interpretations of the terms self-murder and suicide. One was negative to self-murder because of a possible association with criminality, while the other thought that suicide was wrong since she felt that it was used as a way of creating distance to the subject. We discussed this with external experts from suicide survivor groups and with other members of research groups within the field and decided that the wording *"taken his or her own life"* was to be used instead of *"self-murder* "when possible. We chose to keep the term *"self-murder* "since it is more common and recognised among non-professionals in Sweden.

3.2.4.5 The questionnaire

In all, 316 items were included in the bereaved parents' questionnaire: 196 main questions and 120 follow-up questions. Some of the follow-up questions were open-ended with space for free comments. The questionnaire for the non-bereaved parents consisted of 93 main questions, identical or slightly modified versions of the bereaved parents' questions. The main questions can be divided in eight groups with similar content and timeframes (see results paper I). In choosing the cover of the questionnaire, we showed three pictures to the informants that we thought would be suitable: a sunset over a calm sea, a man resting in a flowerbed and Prince Eugene's painting *"The cloud"* (on the cover of the thesis). All informants thought that *"The cloud"* was the most suitable choice and the picture only received positive comments. We received the picture (photo taken by Lars Engelhardt) as well as permission to reprint from Prince Eugens Waldemarsudde.

3.2.4.6 Pilot study

We tested how the parents perceived the contact (means for data collection) and the participation in a pilot study that followed the procedure for data collection described in the main study and had the same inclusion criteria (see subjects and methods). We sent the introductory letter to all individuals (n=36) who had lost a child age 15 to 30, two to five years earlier, according to the Swedish suicide survivors group (SPES) member register. Five persons declined participation without explanation or signs of being upset. Five parents ended their participation; all said that they found the study important but that it had been too mentally exhausting to answer the questions. In all, 29 (81%) parents participated. All but one thought the study was valuable and said they would recommend another bereaved parent to participate. One person answered that he regretted his participation. Three persons stated being negatively affected by the participation, all referring to feelings of sadness. However none of these thought that the negative effect would remain. Fourteen stated being positively affected of which eight thought that the positive effect would remain. Comments from the participants led to minor modification of the questions. The questionnaire was still perceived as too voluminous and was further reduced by removing nearly all follow-up questions on the physiological outcomes. The means of data collection as well as the response rate were further tested by sending the questionnaire to a fraction of the target population.

One mother (in the interview-study) was upset that we contacted her close to the date of her son's death. We therefore decided to extend the time for not contacting participants to at least one month before and one month after the date of the child's death or birth. We also avoided sending introductory letters close to name days and the parents' birth day as well as before public holidays. Several parents expressed how they dreaded the upcoming Christmas (a period of intensified grief). One father who had lost his beloved daughter told me about how he perceived the upcoming Christmas by sending me this drawing.

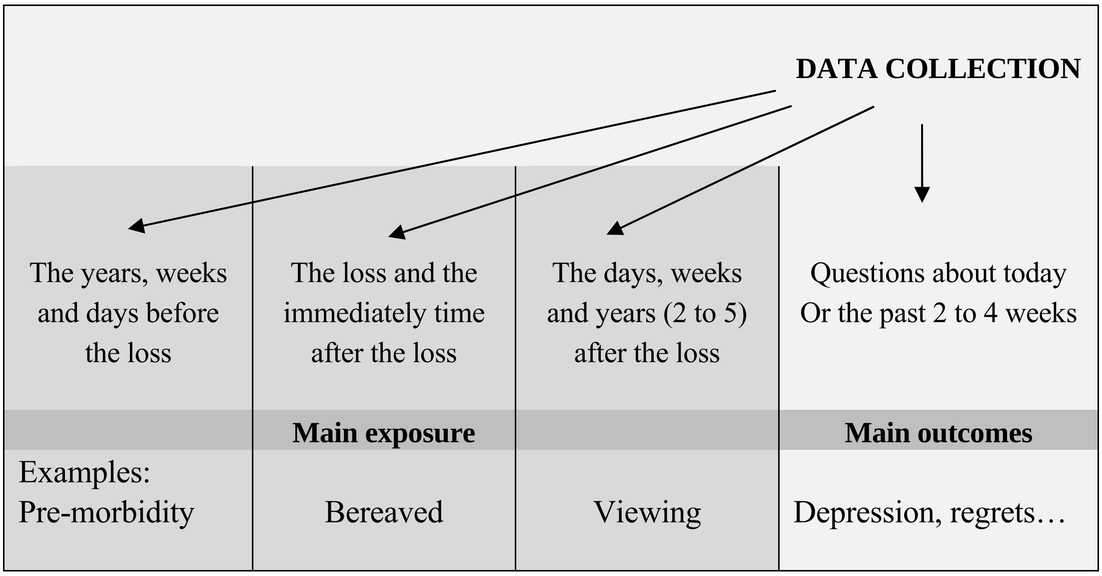
Ilpo Okkola: Kanske finns det jul någonstans..../ *It may perhaps be Christmas somewhere…*

4 SUBJECTS AND METHODS

4.1 Measurements

4.1.1 Time frames used in this thesis

The main exposure in this thesis is the loss of a child through suicide and the main outcomes relate to psychological morbidity during the preceding month. One group of parents lost their children two years earlier and another group lost their children three, four or five years earlier, which enabled us to study how the prevalence of outcomes changed with time since loss. Some data were collected retrospectively; the respondents were for example asked questions about certain events in the immediate period after the loss. The specific time frames are presented together with the questions.



4.1.2 Research participation (Paper II)

We developed our questions regarding research participation from similar questions in previous research[13,26]. The questions: *”Do you think it is valuable to conduct a survey such as this?”, “Do you think this survey has had a negative effect on you?”* and *“Do you think this survey has had a positive effect on you?”* had previously been used in Ulrika Kreicbergs and co-workers’ study on parents that had lost a child through cancer[13]. After each of these questions we added a field for free comments. Resembling Alexandra Eilegård and co-workers’ study on siblings bereaved through cancer[80], we expanded the questions with the follow-up questions: *“If yes, do you think this negative effect will last?”* and *“If yes, do you think this positive effect will last?”*. The questions “*Would you recommend another parent to participate in this study?”*and *“Do you regret participating in this study?”* were developed from similar questions from Kari Dyregrov and co-workers’ research on parents that have lost a child through suicide, SIDS (Sudden infant death syndrome) and accidents[26].

4.1.3 Psychological morbidity (Paper II-IV)

We used four questions to assess the parents' psychological premorbidity (paper III). In the table below, we present the questions as they are printed in the questionnaire (translated into English). All questions had identical response alternatives for their follow-up questions. The non-bereaved parents received identical questions, except for the addition "before and after my child's death".

We define treatment as treatment prescribed by a physician, for example medication, electroconvulsive therapy (ECT) or conversational therapy.

1) Have you **ever been** given treatment for psychological problems such as depression, anxiety, psychosis or personality disorder?
   - ☐ No
   - ☐ Yes → If yes, when did you receive your **first** treatment?,
     - ☐ more than 10 years earlier
     - ☐ during the past 10 years*, **before my child's death**
     - ☐ during the past 10 years, **after my child's death**

Please note! The questions concern the first time you received treatment

2) Have you **ever been** given a psychiatric diagnosis, for example depression, panic disorder, psychosis or personality disorder?'
3) Have you during **a period** of your life medicated against anxiety?'
4) Have you during **a period** of your life medicated against low mood or depression?

* Only *during the past 10 years* for the non-bereaved parents

The study-specific questions used to assess psychological morbidity such as anxiety were phrased as in the example below and are presented in the results section (table x).

Have you taken medication against low mood or anxiety during the preceding month?

- ☐ No
- ☐ Yes, occasionally
- ☐ Yes, 1-3 days per week
- ☐ Yes, 4-5 days per week
- ☐ Yes, 6-7 days per week

If yes, what medication have you taken against anxiety during the preceding month?:

4.1.4 Psychometrically validated scales (Paper II-IV)

When choosing scales we considered psychometric properties, relevance and whether the scale was suitable to be included in our questionnaire (see methodological discussions). We found several scales with high reliability and validity that had been used and tested in study-populations similar to ours[81]. Among these scales we chose the nine-item depression scale of the Patient Health Questionnaire (PHQ-9), the two-item Generalized Anxiety Disorder scale (GAD-2) and the Alcohol Use Disorders Identification Test (AUDIT). We chose these scales since their items were constructed like the other questions in our questionnaire and because of their compactness. The scales are also well known and frequently used in Sweden.

4.1.5 Harmful alcohol consumption (AUDIT)

The Alcohol Use Disorders Identification (AUDIT) was developed by the World Health Organization (WHO) as a simple method for screening for excessive drinking and to assist in brief assessment[82,83]. AUDIT consists of 10 items with five response alternatives (for the last two items only three), scored from 0 to 4 score with a maximum score of 40. The most common cut-off is 8 when assessing hazardous or harmful alcohol consumption, although lower cut-off points have been suggested, especially when screening female populations[84-86]. AUDIT is sensitive to hazardous drinking as well as severe alcohol problems which makes it suitable for studies of the general population. The Swedish version of the test shows good psychometric properties and has been used to assess alcohol use in large Swedish populations[84,87,88].

The AUDIT questionnaire items

1. How often do you have a drink containing alcohol?
2. How many drinks containing alcohol do you have on a typical day when you are drinking?
3. How often do you have six or more drinks on one occasion?
4. How often during the last year have you found that you were not able to stop drinking* once you had started?
5. How often during the last year have you found that you failed to do what was normally expected from you because of drinking?
6. How often during the last year have you found that you needed a first drink in the morning to get yourself going after a heavy drinking session?
7. How often during the last year have you found that you had a feeling of guilt or remorse after drinking?
8. How often during the last year have you been unable to remember what happened the night before because you had been drinking?
9. Have you or someone else been injured as a result of your drinking?
10. Has a relative or friend or a doctor or other health worker been concerned about your drinking or suggested you cut down?

Response sets:

1,3-8 *"never", "monthly or less", "2-4 times a month", "2-3 times a week"* and *"4 or more times a week"*
2 *"1-2", "3-4", "5-6", "7-8"*, and *"more than 10"*
9-10 *"No", "Yes, but not in the last year"*, and *"Yes, during the last year"*

Table 3. The Alcohol Use Disorders Identification (AUDIT). The Swedish certified translation used in the questionnaire can be found at http://www1.psykiatristod.se

4.1.6 Depression (PHQ-9) and anxiety (GAD-2)

PHQ-9 and GAD-2 were initially developed from the Patient Health Questionnaire (PHQ), a self-administered version of The Primary Care Evaluation of Mental Disorders (PRIME-MD)[89]. The structured interview guide PRIME-MD was developed to diagnose the most common types of mental disorders presented in the medical health care populations[90]. This tool to detect and monitor common mental disorders, although efficient, was however sometimes perceived as too time consuming for clinical use and was therefore complemented with the self-administered PHQ. Combinations of different subscales from PHQ have thereafter been developed and tested in clinical practice and research[89,91,92]. One of the most widely used sub-scales from PHQ is the nine-item depression scale PHQ-9 and the seven-item Generalized Anxiety Disorder scale GAD-7. The original versions of these scales use verbal options for response sets but numerical response sets have also been used and tested. For example, the verbal option has sometimes been replaced by specifying the number of days over the past one or two weeks when used in surveys[89].

The PHQ and GAD can be used either as a diagnostic algorithm to make a probable diagnosis or as a continuous measure with scores and cut-off points. The scores of PHQ-9 range from 0 to 27 and the cut-off points of 5, 10, 15 and 20 have been suggested to represent mild, moderate, moderately severe and severe levels of depressive symptoms[89]. A review including more than 9,000 individuals suggests that with a cut-off ten, PHQ-9 has a sensitivity of 0.77 to 0.88 and a specificity of 0.88 to 0.94[89]. GAD-7 was originally developed to assess “General Anxiety Disorder” (GAD) but also proved to have good sensitivity and specificity as a screening for panic, social anxiety and post-traumatic stress disorder. The high sensitivity and specificity of GAD-7 was just marginally reduced when only the first two items (the core diagnostic criteria for GAD) were used (GAD-2). We therefore chose to use GAD-2 instead of GAD-7. The scores for GAD-2 range from 0 to 3 with a total severity score of 6 and the cut-off score of three has been suggested as a screening point for clinically significant anxiety (recommendations of further assessment)[89,93]. Considering the results from the preparatory study we changed the verbal response set to a numerical set. For clarity we also divided question 6 and 8 in PHQ-9 into two questions (see table on next page). We assessed depression by PHQ-9[59] and anxiety with GAD-2[93] using a Swedish certified translation[60].

PATIENT HEALTH QUESTIONNAIRE-9 (P H Q - 9)

Over the last 2 weeks, how often have you been bothered by any of the following problems?

(Use "✓" to indicate your answer)	Not at all	Several days	More than half the days	Nearly every day
Red text=added text Blue text=removed text	Not at all	1–3 days a week	4–5 days a week	6-7 days a week
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. (6a) Feeling bad about yourself — or that you are a failure or (6b) Feeling that you have let yourself or your family down[1]	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. (8a) Moving or speaking so slowly that other people could have noticed? Or the opposite —(8b) being so fidgety or restless that you have been moving around a lot more than usual[1]	0	1	2	3
9.Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3
10. Feeling nervous, anxious or on edge[2]	0	1	2	3
11. Not being able to stop or control worrying	0	1	2	3

FOR OFFICE CODING *0* + ______ + ______ + ______ =Total Score: ______

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all	**Somewhat difficult**	**Very difficult**	**Extremely difficult**
☐	☐	☐	☐

Developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke and colleagues, with an educational grant from Pfizer Inc. No permission required to reproduce, translate, display or distribute.

[1] Using the highest score of one of the two questions.
[2] The first two items in GAD-7 (GAD-2).

Table 4. The nine-item depression scale of the Patient Health Questionnaire (PHQ-9), The Swedish certified translation used in the questionnaire can be found at http://www.phqscreeners.com.

4.2 Data management

With the help of a research assistant we entered the answers from the questionnaires into a database in Microsoft Access. The assistant was seated next to me to be easily assisted in queries (most of these were about interpretation of handwritten comments). Ambiguities, such as double-marks and in-between marks were registered in a separate list to make them traceable. When a whole spread of questions was missing, the assistant sent a copy of the missing questions along with an invitation to complete them to those respondents that had chosen not to be anonymous. Retrieved answers to the missing spread of questions were entered into the dataset; otherwise no imputation of data was done at this stage (see statistical analysis). To minimise the risk of entering erroneous data the database was constructed only to permit entries of appropriate values for every question. The reliability of the data entry was tested by re-inputting 10% of randomly chosen questionnaires (excluding the free-hand text). Before closing the dataset for new entries double-marks and in-between marks were, when feasible, solved by alternating between entering the lowest value and the highest value given, respectively. The imputations were done in the syntax file and not in the original data.

4.2.1.1 Statistical tests

We performed the statistical tests at the 5% significance level, unless otherwise stated. All statistical analyses were done by using the IBM SPSS Statistics software, V.19.0. In the first two papers in this thesis we used descriptive statistics to summarise our findings and to investigate relationships between two different variables (cross-tabulations), but did not use statistical analyses for further comparison between groups or values (se discussion paper II).

In the third and fourth paper we tested for statistical differences in characteristics between the bereaved and the non-bereaved participants using Pearson's χ^2 test and Wilcoxon-Mann-Whitney's test. We dichotomised the scores derived from the psychometric scales using commonly recommended cut-offs.[85,94,95] When deciding upon cut-offs for the study-specific questions we considered results from previous studies as well as the clinical importance of the symptom. We thereafter used logbinomial regression to calculate relative risks (RR) and calculated RR of the different outcomes adjusting for potential confounders, one variable at a time. For modelling involving more than two explanatory variables, we had to use OR estimated through logistic regression, since log-binomial regression did not converge and failed to produce estimates, a well-known issue with this model[96]. We performed a variable selection among the possible confounders, using logistic regression with forward selection in order to identify those variables most strongly related to the main outcomes in each group (see papers for details about the selection procedures). Since we wanted to maximise the possibility of finding other explanatory factors that could potentially disprove the assumed effect of bereavement, we used a liberal inclusion criterion allowing variables up to the 15% significance level entry. In addition to using dichotomised scores we also used Wilcoxon-Mann-Whitney's test to assess the association between the level of exposure and the levels of psychological outcomes.

With the exception of AUDITs second item, missing values were not a great concern during the analyses in this thesis. Individuals that had missed two or more items on the psychometric scales were excluded from the analyses, as were those who had missed single-item questions. In AUDIT, the first item *(How often do you have a drink containing alcohol?)* was missed by 2% of the respondents and the second item *(How many drinks containing alcohol do you have on a typical day when you are drinking?)* by 12%. To reduce the number of missing individuals we imputed the lowest value *"1-2"* (score 0) to the second item if the respondents has missed the second item and had answered *"never"* on the first item. Otherwise we did no imputations of the data in this thesis.

4.3 Data collection

We contacted all eligible parents (see study population) by means of an introductory letter followed by a telephone call after two weeks[14,26,80,97]. To minimise the risk of upsetting parents who were uncertain about the cause of death or believed that the cause of death was something other than suicide, we only included deaths registered as suicides [International Classification of Diseases, Tenth Revision (ICD-10) code X60–84] and not those for whom the cause of death was uncertain (ICD-10 code Y10–34). Although this may appear to be unusual, we had to consider the possibility that a few of the deaths had been erroneously classified as suicide. In the introductory letter we therefore addressed the parents as *"someone who has lost a son or daughter in a sudden death"* and *"someone who has not lost a son or daughter"* and emphasised that the questionnaires were developed together with suicide-bereaved parents. We also forewarned participants that some of the questions could raise difficult emotions, although participants in similar studies often perceived the participation as valuable[14,22,26,98]. In the introductory letter we emphasised that participation was voluntary and we informed them about the possibility to end participation at any time without further explanation[14]. Our names and telephone numbers, one of which was toll free, were listed and the parents were encouraged to contact us with questions or if they needed support at any time during the study. We wanted the contact to be personal and wrote the name and addresses by hand. We also used pleasant stamps and refrained from using the university logo on the envelope, although this has been shown to increase the response to postal questionnaires[99].

For ethical reasons we made it easy to decline participation without any need for personal contact with the researchers by making it possible to decline by means of email, letter, text message or by leaving a message on an answering machine. We only sent around 50–100 introductory letters each week, since we wanted to have the time to attend to both incoming and follow-up telephone calls. This time-frame also enabled us to stop the data collection if the results were to indicate that the participants were being harmed in any way. We avoided contact on the date of the death (one month before and after) as well as close to official holidays, birthdays and name days. All events as well as the parents' comments were carefully noted and registered in the database. The telephone calls were made by me and an experienced research assistant.

All specific questions were answered by me, since we wanted to approach the respondents in the same way. To avoid distress and personal intrusion, all calls were made using a sensitive 'step-by-step approach', meaning that we started with general questions and were responsive to any indication that it was time to stop probing. A denial was accepted immediately without challenging the decision or trying to persuade the parent to participate. We noted spontaneous motivations for the denials and sorted according to categories established in the pilot study. Usually we started the telephone conversation by asking the parent if he or she had read the introductory letter and whether the parent had any questions. If the informant did not decline or agreed to participate directly, which was the common case, we asked if he or she wanted to look at a questionnaire. If the answer was yes, we then asked if he or she had lost a son or daughter. If the answer was yes, we explained that the questionnaire had been developed in cooperation with suicide-bereaved parents, which often resulted in a comment about their own son or daughter's cause of death. A few parents told us that the cause of death was unknown to them or that their child had died in an accident or had been murdered. These parents were invited to answer the questions that they felt were relevant for them.

We were always prepared to listen for as long as needed[26]. All parents that expressed a need for support were offered the chance to talk with me, since I have a long experience working with traumatised patients and suicide-related issues. A few parents needed further professional intervention and were either aided in obtaining appropriate help or were offered the chance to speak with the main-supervisor, who is a physician, specialised in psychiatry as well as suicidology. We emphasised that participation could be ended at any time without further explanation and also informed the parent about the possibility to answer the questionnaire anonymously. At each telephone call we asked for consent to call again if the parent had not returned the questionnaire within a time-frame that we had agreed on. The same person who initiated the contact usually phoned the follow-up call if nothing else was agreed.

4.4 Identification of the study-population

We identified all parents that had lost a 15 to 30 year old son or daughter through suicide 2–5 years earlier by linkage of the Swedish Cause of Death Register and the Multi-generation Register. To be included in the study, the parent had to be born in one of the Nordic countries, be able to communicate in Swedish and have an identifiable address and telephone number. Furthermore, parents that had lost more than one child were excluded. We also identified a random sample of non-bereaved parents matched (1:2) for age, gender, living area, marital status, number of children, and with a child born the same year as the deceased child through the Swedish Population Register. To keep our procedures within the bounds specified by the Swedish 'law of secrecy', the identification of the suicide-bereaved and the matching of non-bereaved parents was done by the register holders and the researchers did not know whether the parents were bereaved or non-bereaved until they chose to reveal this themselves. In all, 915 suicide-bereaved and 508 non-bereaved parents were identified as eligible (targeted study population) and were sent an introductory letter. We were able to establish contact with 1410 of 1423 (99%) of the eligible parents. We started the data collection in August 2009 and the last questionnaire was returned in December 2010. Initially, 782 (85%) suicide-bereaved and (82%) non-bereaved parents agreed to participate; while 666 (73%) bereaved and 377 (74%) non-bereaved parents returned their questionnaires (figure 8 below).

4.4.1 Non-participants

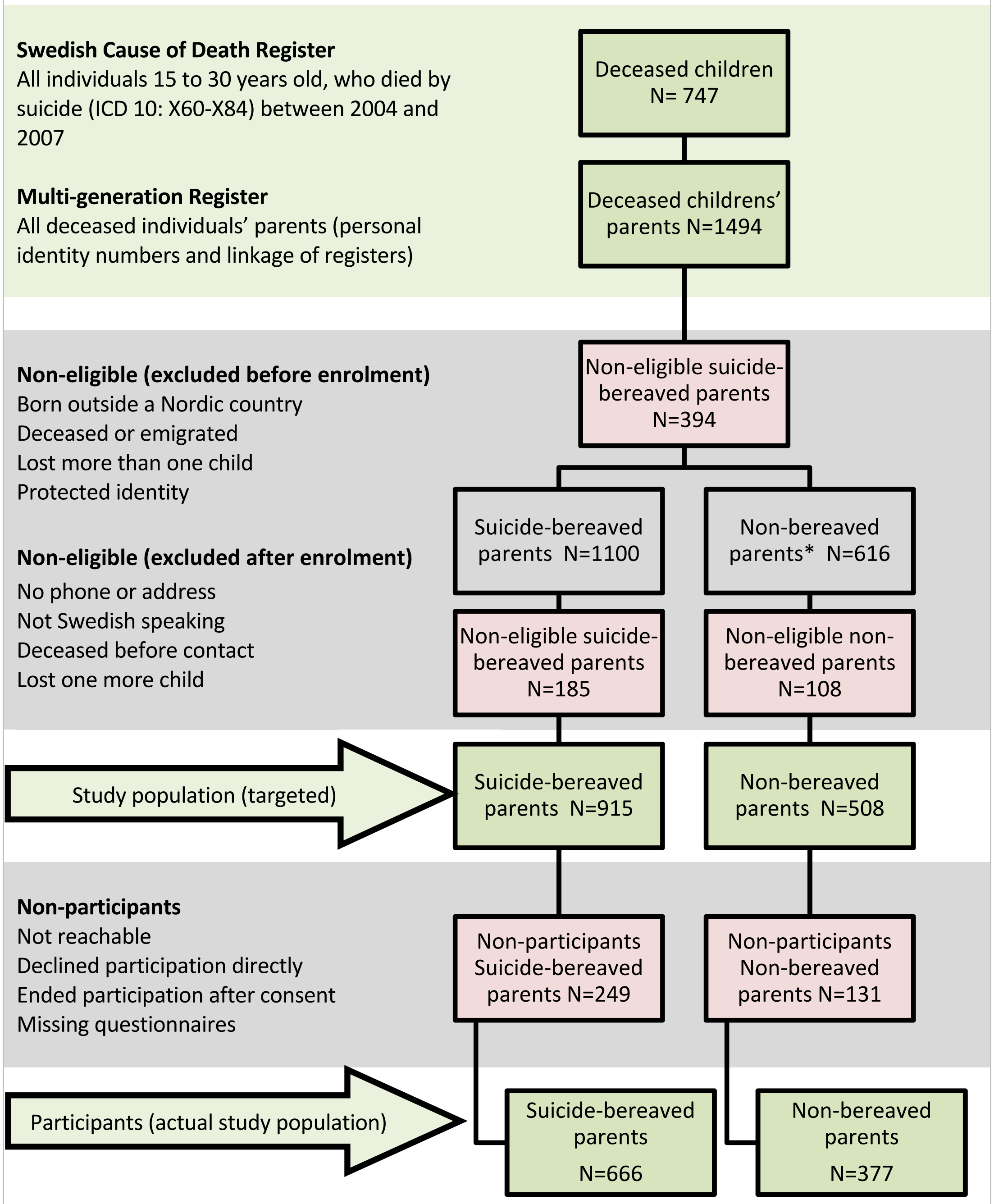
4.4.1.1 Declined participation (Paper II)

A significant minority seemed to be offended by the contact per se; six persons expressed anger when they declined participation and two were shocked and distressed at first. Essentially we got no indication that the contact (or participation) caused any long-term distress (see paper II). Among the other parents, most parents that declined participation did so in a friendly manner without hesitation or signs of distress. Of those who motivated their decision not to participate, 22 referred to ongoing "psychological distress or ill-health" and four to "somatic diseases or conditions". Similar reasons were given for the 22 cases in which participation was declined by another person. Twenty-one parents said that they did not participate in research as a matter of principle and seven persons referred to "lack of time". Six persons did not want to participate referring to the cause of death as being something other than suicide.

4.4.1.2 Agreed to participate but ended participation

Of the parents who agreed to participate, 31 ended their participation due to "psychological distress or ill-health" (two had a somatic disease) that they, according to their own information, had had before the contact with us. Around half of these parents received support over the telephone. Several had ongoing contact with other health professionals and others were supported in finding a suitable contact. Around 50 parents ended their participation without giving any explanation and around 50 referred to "lack of time" or a "complicated life situation".

4.5 Study population



* The non-bereaved parents were matched with the suicide-bereaved parents in a ratio 1:2 on the following variables: marital status, age, gender, living area and number of children. All non-bereaved had a child in the same age as the deceased child's age. All fulfilled the same inclusion criteria as the suicide-bereaved parents: were born in a Nordic country and had a listed telephone number and address.

Figure 8. Participation and non-participation among suicide-bereaved and non-bereaved parents

4.6 Participants

Participants	Suicide-bereaved n=666 (73%)	Non-Bereaved n=377 (74%)
Sex – no. (%)		
Fathers	283 (42)	166 (44)
Mothers	383 (58)	211 (56)
Age – yr		
Fathers, Median (IQR)	58 (53–62)	59 (54–62)
Mothers, Median (IQR)	55 (51–59)	54 (50–59)
Children – no. (%)		
One child	71 (11)	43 (11)
Two children	241 (36)	139 (37)
Three or more children	350 (53)	193 (51)
Not stated	4 (<1)	2 (<1)
Family constellation at time of study – no. (%)		
Living with a partner	477 (72)	271 (72)
Has partner but lives alone	44 (7)	28 (7)
Single	121 (18)	67 (18)
Widow, widower	18 (3)	11 (3)
Not stated	6 (<1)	0 (0)
Residence area – no. (%)		
Rural	162 (24)	77 (20)
Village (population < 10,000)	153 (23)	97 (26)
Small town (population < 50,000)	128 (19)	73 (19)
Town (population < 200,000)	117 (18)	62 (16)
Larger town (population > 200,000)	97 (15)	68 (18)
Not stated	9 (1)	0 (0)
Country of birth – no. (%)		
Born in Sweden	630 (94)	371 (98)
Born in other Nordic country	36 (6)	6 (2)
Level of education – no. (%)		
Elementary school or less	146 (22)	73 (19)
Junior college	271 (41)	158 (42)
College or university (< 3 years)	82 (12)	55 (15)
College or university (> 3 years)	159 (24)	91 (24)
Not stated	8 (1)	0 (0)
Source of income – no. (%)		
Employed or self-employed	498 (75)	303 (80)
Old-age pension	59 (9)	38 (10)
Disability pension	61 (9)	21 (6)
Unemployment fund	25 (4)	6 (2)
Other	16 (2)	9 (2)
Not stated	7 (1)	0 (0)
Yearly income in Swedish crowns – no. (%)		
0-99,000 SEK	34 (5)	10 (3)
100 000-199,000 SEK	120 (18)	64 (17)
200 000-399,000 SEK	388 (58)	240 (64)
400,000 SEK or more	109 (16)	59 (16)
Not stated	15 (2)	4 (1)
Religion – no. (%)		
Do not believe in God	355 (53)	216 (57)
Believes in God	287 (43)	150 (40)
Not stated	24 (4)	11 (3)

Table 5. Participation rates and characteristics among bereaved and non-bereaved parents

5 RESULTS

5.1 The questionnaire and the hypotheses (Paper I)

The aim of our preparatory study was threefold; firstly we wanted to identify factors of importance for the development of psychological morbidity after losing a child through suicide (hypothesis generating). Secondly we needed to create questions that assessed these factors. Thirdly we had to test the means for data collection (paper I, II). One finding from the qualitative analysis was that the parents laid great emphasis on describing the child and how the child was before any trouble started. The parents also emphasised their perceived experiences of the child's professional help (or lack of professional help) during the time before the suicide. We created several questions with space for free comments to further explore these experiences (will be published in upcoming papers). The overall aim of our study was, however, to improve the professional care provided in the aftermath of a suicide loss (postvention). Thus most of our hypotheses concern "the death" and the "time after the death" rather than the "time before the death". For the same reason most hypotheses involve comparisons within the group of suicide-bereaved parents rather than between the bereaved and non-bereaved. The papers in this thesis are the first to be developed from this material and we therefore chose to present how some of our main outcomes are distributed among the bereaved in comparison with the non-bereaved parents (paper III). Below are some examples of working-hypotheses derived from the preparatory study (paper I).

Suicide-bereaved and non-bereaved parents

- Bereaved parents have higher prevalence of self-rated anxiety, depression, harmful alcohol consumption and sick-leave in comparison with non-bereaved parents (paper III)
- The loss, rather than previous psychological morbidity, explains excess psychological morbidity among bereaved parents in comparison with non-bereaved parents (paper III)

Suicide-bereaved parents

- Parents who chose to view the body do not regret the viewing (paper IV)
- Viewing the body during unworthy circumstances is associated with higher prevalence of intrusive thoughts and nightmares (paper IV)
- Receiving the death notification close to the time of death is associated with lower prevalence of psychological distress (paper IV)
- Parents' excess levels of psychological morbidity are reduced by time since the loss
- Believing that the child's suicide was caused by psychiatric illness is associated with lower prevalence of self-rated shame and feelings of guilt
- Parents who have talked with their child about death prior to the suicide do not regret this
- Worries about the child committing suicide prior to the suicide is associated with lower prevalence of psychological distress
- Parents that lack someone to share their innermost feelings with have higher prevalence of psychological distress than parents who do not

5.1.1.1 Internal response rate

Altogether 316 items were included in the bereaved parents' questionnaire: 196 main questions (designed to be answered by everyone) and 120 follow-up questions. The first two sections, including the main outcomes measured by PHQ-9 and GAD-2, were answered by nearly all participants. The overall internal response rate was also high among the questions in the third and sixth section. The questions in the fourth, fifth, seventh and, eighth section had a somewhat lower response rate (figure 9). In all, the mean answering rate for the main questions was 98%.

Nine questions had an internal response rate of 90% or less; four concerned experiences related to the death notice (section four); four support groups (section six), and one question was an item included in the psychometric scale AUDIT (section seven). The internal response rate was greatly improved during the validation process. For the questions that we did not alter during the validation process, the response rates were consistent throughout the validation process and main data collection. The validity and reliability are discussed in the methodological discussion

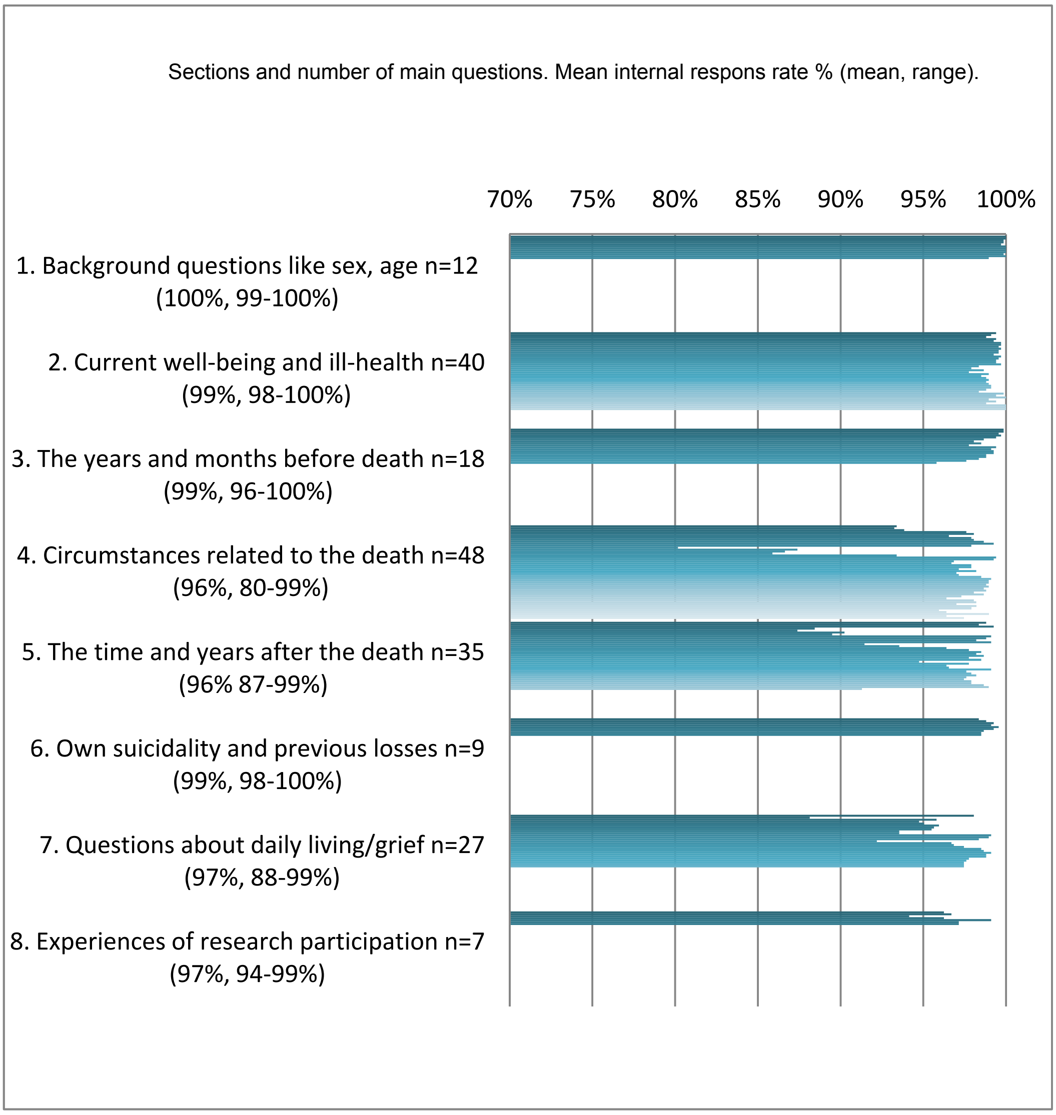


Figure 9. Sections, number of main questions, and internal response rate in the bereaved parents questionnaire

5.2 Ethical considerations (Paper II)

5.2.1.1 Positive effects of participation

Ninety-five percent of the bereaved parents (92% of the non-bereaved) answered that they thought that the study was valuable. Most (91%) bereaved parents (76% of the non-bereaved) would recommend participation to another parent. Furthermore half of the bereaved parents (28% of the non-bereaved) reported being positively affected by their participation, and more than half (59%) thought that the positive affect might last (53% of the non-bereaved). Among the bereaved parents, 79% gave a free comment in response to the question on being positively affected by participation and the comments mainly fitted into one of three categories:

- Gratitude for the opportunity to relate experiences and for interest in the child, situation and subject.
- Hope that relating their experiences might help others in a similar situation and improve care provision.
- Experience of being helped by working through memories and feelings raised by answering the questionnaire.

Among the non-bereaved parents, 75% wrote comments in reply to the question and most of them referred to being grateful for the opportunity to help others and also for having their child and their health. Another positive effect was that several participants and non-participants, that described major suffering due to psychological morbidity, received professional help as a result of the contact with us.

5.2.1.2 Negative effects of participation

Eleven percent of the bereaved parents (1% of the non-bereaved) reported being negatively affected at the end of their participation. Among these parents, two answered they thought that the negative effect might last, one was bereaved and the other one was not. Of the 70 bereaved that reported being temporarily negatively affected, 51 referred to painful memories in their written comments and 10 wrote that they felt sad or depressed. Some commented that these feelings were not necessarily bad for them and 51% reported being both negatively and positively affected by their participation. Among the bereaved parents that reported being negatively affected 20% were moderately to severely depressed (score ≥ 10 on PHQ-9) in comparison with 18% among all bereaved. Four percent of the bereaved parents (5% of the non-bereaved) answered they regretted their participation. Of the 25 bereaved that regretted participation; eight referred to painful memories and sadness; five to too many questions and one parent perceived the questionnaire as impersonal. Of the 17 non-bereaved parents, only four commented on their answers; one referred to ongoing cancer disease, one that she had not lost a child, one to research participation in general and one to low mood.

5.3 The ethical protocol (Paper II)

When planning our study, we carefully considered ethical regulations and recommendations as well as findings from previous studies. The methods for contact and data collection were thereafter refined during the preparatory study (paper I). In table 5 below, we summarise the ethical considerations applied throughout our study.

SUMMARY OF ETHICAL CONSIDERATIONS

Preparation

- Carefully plan the inclusion criteria
- Same introductory letter to bereaved and non-bereaved
- Carefully consider when to send the introductory letter e.g. avoiding death and birth dates
- Make time, be prepared for long conversations with presumptive informants
- Create a database for all communication and contact information

Introductory letter

- Contact information to researchers e.g. toll free telephone number, availability 24-hours
- Focus of the study and the questionnaire
- Possible negative and positive experiences of participation
- Option to end participation at any time without explanation
- Opportunity to decline contact or participation
- Several ways to decline contact or participation, e.g. by phone, e-mail and sms
- Inform about upcoming phone call – when and by whom
- Send some letters at a time (possibility to stop the data collection if indication of harm)
- Decide how many letters to send at a time (time to attend to reactions and questions)

Telephone call

- Carefully consider when to make the phone call e.g. avoiding death, name and birth dates
- Telephone call by trained interviewer
- Careful sensitive “step by step” approach going from general questions to more detailed ones
- Being responsive and prepared for questions and needs of support
- Provide support and help with referral if needed
- Encourage contact again if help or support is needed
- Give enough time for questions and support
- Accept a denial to participate directly without further probing
- Repeat option to end participation at any time
- Ask for consent to send a questionnaire
- Ask for consent to call again within a time agreed upon

During participation

- Continuity throughout the study with the same trained interviewers
- Interviewers being available and prepared for questions and support 24-hours
- Provide support and help with referral if needed
- Give enough time for questions and support
- Give enough time for participation
- Ask for consent to call again during participation

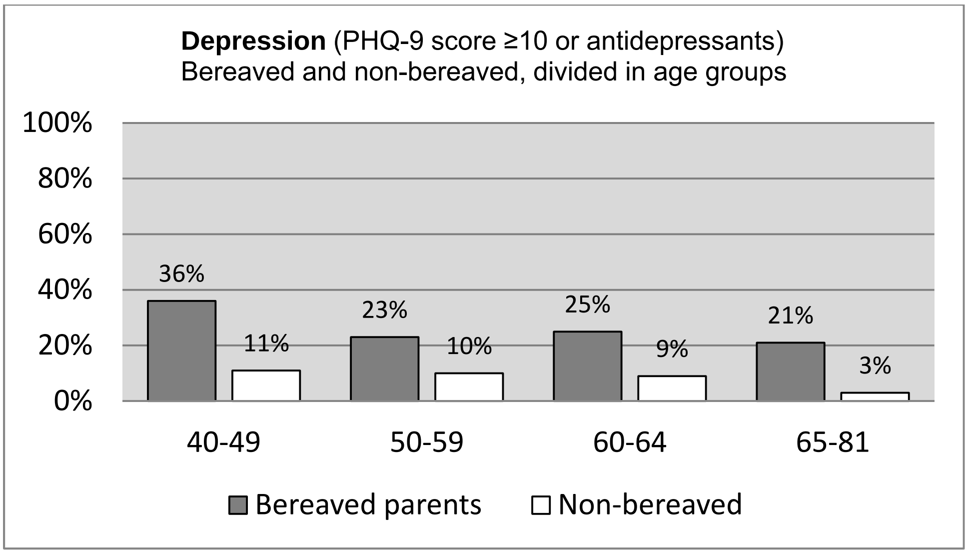
Table 6. Summary of ethical considerations

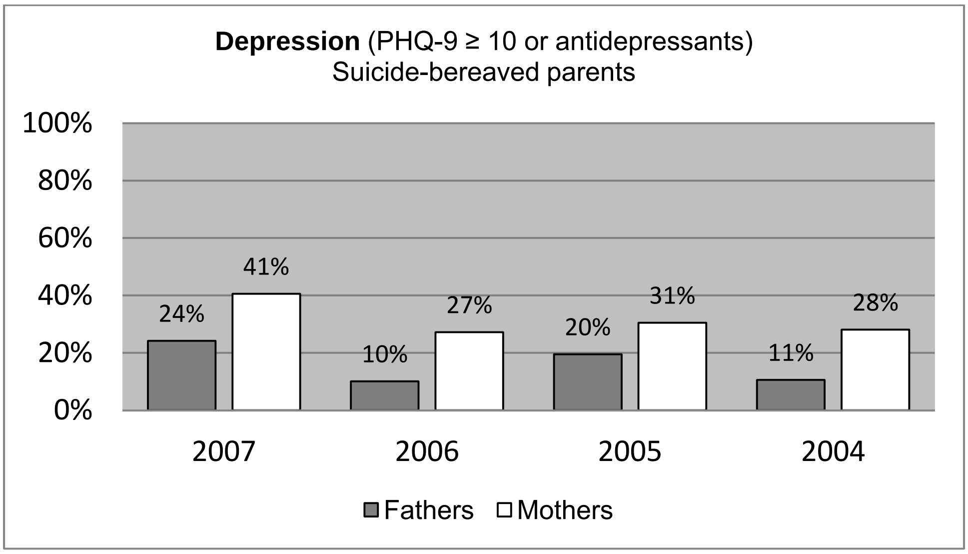
5.4 Psychological morbidity (Paper III)

One aim of our study was to investigate the prevalence of clinically significant psychological morbidity among parents bereaved to suicide, two to five years earlier. We also present whether there were differences in psychological premorbidity between the bereaved and non-bereaved parents, and the association between bereavement and depression among parents with and without psychological premorbidity.

5.4.1.1 Depression

Single-item question: 21% of the bereaved parents reported that they had felt "low or depressed" at least "1-3 days a week" during the last month (6% of the non-bereaved, RR 3.8; 95% CI 2.5 to 5.9). **PHQ-9:** 18% of the bereaved parents scored 10 or more on PHQ-9 (moderate to severe depression) and 7% of the non-bereaved (RR 2.3; 95% CI 1.6 to 3.5) (table 6). Split by sex, the prevalence of depression was 23% in bereaved mothers (12% in non-bereaved mothers) and 10% in bereaved fathers (4% in non-bereaved fathers). Altogether, 25% of the bereaved parents were currently taking antidepressants or were moderate to severely depressed according to PHQ-9 (9% of the non-bereaved, RR 2.7; 95% CI 1.9 to 3.8).





	Suicide-bereaved no.(%)	**Non-bereaved** no.(%)	Relative risks RR (95% CI)
Anxiety and depressive symptoms			
During the preceding month[1]			
Persisting anxiety			
Occasionally or more often	145/664 (22)	29/377 (8)	2.8 (1.9-4.1)
Yes, 1-3 days a week or more	41/664 (6)	4/377 (1)	5.8 (2.1-16.1)
Anxiety attacks			
Occasionally or more often	254/664 (38)	48/377(13)	3.0 (2.3-4.0)
Yes, 1-3 times a week or more	53/664 (8)	5/377 (1)	6.0 (2.4-14.9)
Awakening with anxiety during night			
Occasionally or more often	210/663 (32)	50/377(13)	2.4 (1.8-3.2)
Yes, 1-3 times a week or more	40/663 (6)	5/377 (1)	4.5 (1.8-11.4)
Awakening with anxiety in the morning			
Occasionally or more often	196/664 (30)	39/377 (10)	2.9 (2.1-3.9)
Yes, 1-3 times a week or more	46/664 (7)	2/377 (<1)	13.0 (3.2-53.5)
Low or depressive mode			
Occasionally or more often	523/663 (79)	165/377 (44)	1.8 (1.6-2.0)
Yes, 1-3 days a week or more	141/663 (21)	21/377 (6)	3.8 (2.5-5.9)
Depression (PHQ-9)[2]			
Score 10 or more	115/655 (18)	28/374 (7)	2.3 (1.6-3.5)
Score 15 or more	52/655 (8)	4/374 (1)	7.4 (2.7-20.4)
Score 20 or more	16/655 (2)	1/374 (<1)	9.1 (1.2-68.6)
Anxiety (GAD-2)[3]			
Score 2 or more	139/658 (21)	22/374 (6)	3.6 (2.3-5.5)
Score 3 or more	55/658 (8)	3/374 (<1)	10.4 (3.3-33.0)
Risky alcohol consumption (AUDIT)[4]			
Score 8 or more	76/643 (12)	28/375 (7)	1.6 (1.0-2.4)
Score 16 or more	19/643 (3)	7/375 (2)	1.6 (0.7-3.7)
Score 20 or more	12/643 (2)	2/375 (<1)	3.5 (0.8-15.6)
Medication			
During the preceding month[1]			
Sleeping medication			
Occasionally or more often	146/664 (22)	43/377 (11)	1.9 (1.4-2.6)
Yes, 1-3 days a week or more	82/664 (12)	20/377 (5)	2.3 (1.5-3.7)
Antidepressant medication			
Occasionally or more often	107/664 (16)	15/375 (4)	4.0 (2.4-6.8)
Yes, 1-3 days a week or more	99/664 (15)	13/375 (3)	4.3 (2.4-7.6)
Anxiolytic medication			
Occasionally or more often	66/662 (10)	14/375 (4)	2.7 (1.5-4.7)
Yes, 1-3 days a week or more	49/662 (7)	8/375 (2)	3.5 (1.7-7.2)
Antidepressant medication[1] **and/or score 10 or more on PHQ-9**[2]	167/665 (25)	35/377 (9)	2.7 (1.9-3.8)

[1] “No”,” Yes occasionally”, “Yes 1-3 days/times a week”, “Yes 4-5 days/times a week”, “Yes 6-7 days/times a week”
[2] The nine item depression scale (PHQ-9) scores range from 0 to 27
[4]The 2-item Generalized Anxiety Disorder scale (GAD-2) scores range from 0 to 6
[5]The Alcohol Use Disorders Identification Test (AUDIT) scores 8 or higher (range from 0 to 40)

Table. 7. Psychological morbidity among suicide-bereaved and non-bereaved parents.

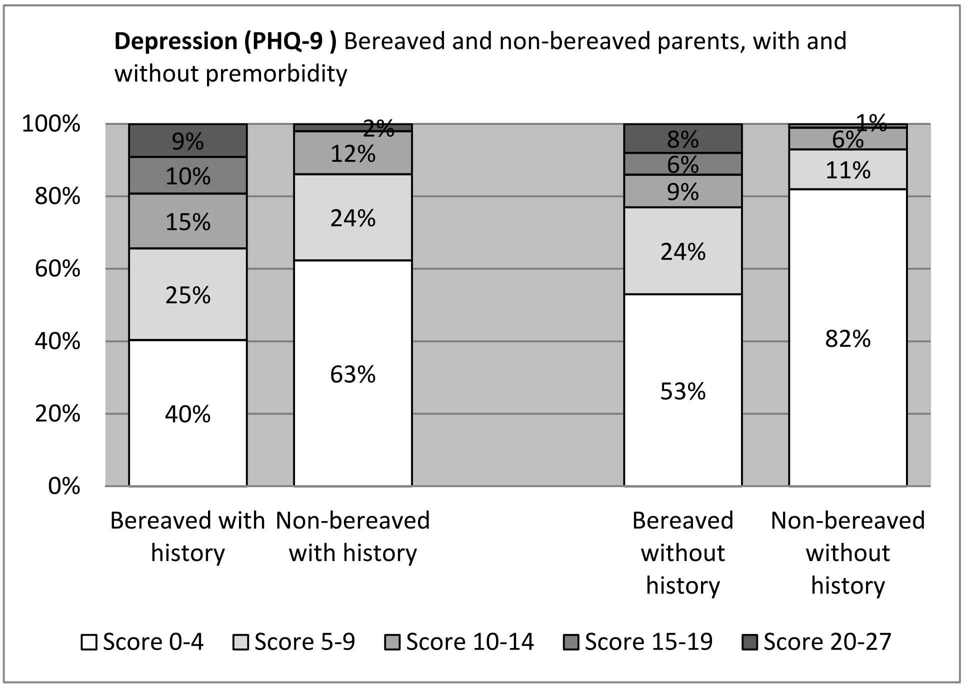
5.4.1.2 Psychological premorbidity

Fourteen percent of the bereaved and 14% of the non-bereaved parents (RR 1.0; 95% CI 0.8 to 1.4) reported psychological problems (received treatment or had been diagnosed) starting more than 10 years earlier. The bereaved parents had a somewhat higher prevalence on each of the single questions (table 7).

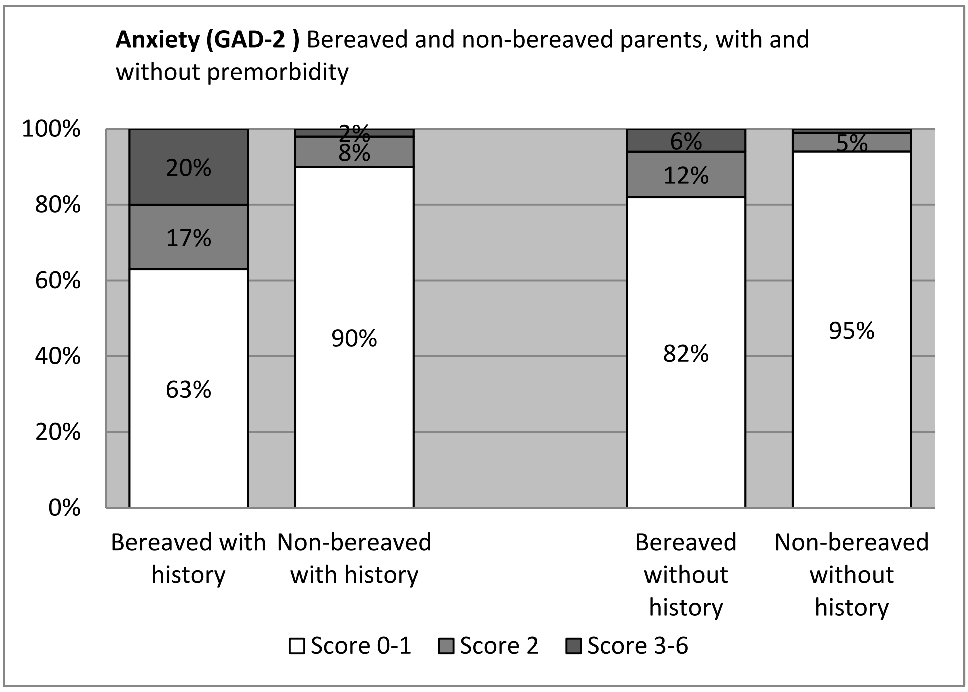
	Suicide-bereaved	**Non-bereaved**	
Participants with:	no./total no. (%)		(CI 95%)
First treatment for psychological problems more than 10 years earlier	71/659 (11)	38/373 (10)	1.0 (0.7 to 1.5)
First psychiatric diagnosis more than 10 years earlier	45/651 (7)	18/373 (5)	1.4 (0.8 to 2.4)
First medication against anxiety more than 10 years earlier	52/657 (8)	24/377 (6)	1.2 (0.8 to 2.0)
First medication against low mood or depression more than 10 years earlier	61/655 (9)	23/373 (6)	1.5 (1.0 to 2.4)
Any of the above (treatment or diagnosis) more than 10 years earlier	**94/663 (14)**	**51/377 (14)**	**1.0 (0.8 to 1.4)**

Table 8. Psychological premorbidity among suicide-bereaved and non-bereaved parents. The questions and response are further presented in the method section (as written in the questionnaire)

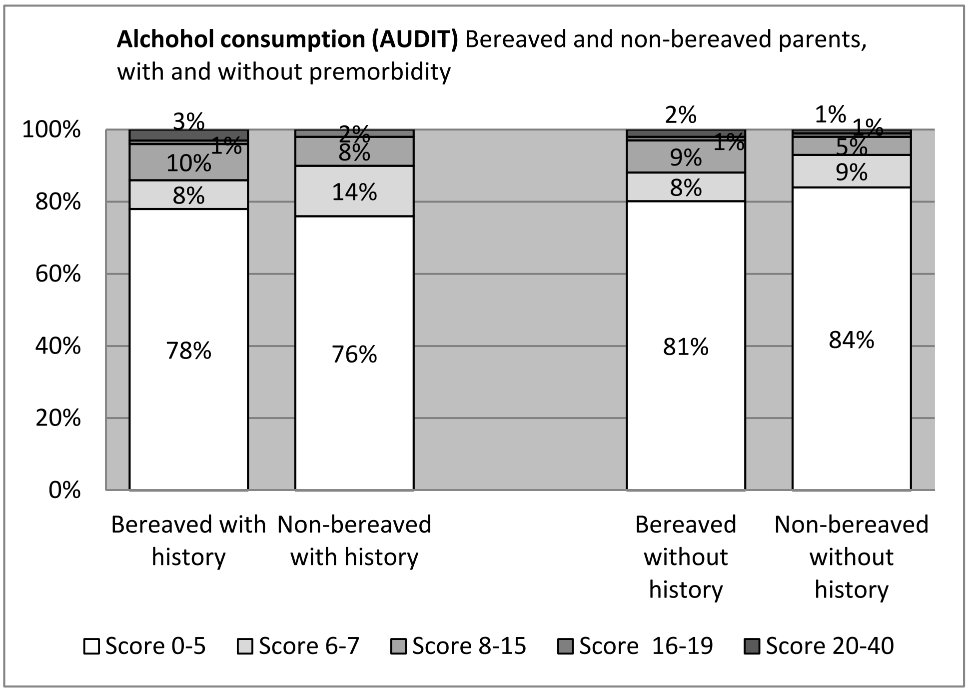
When stratified according to psychological premorbidity the prevalence of: Moderate to severe depression: Thirty-five percent of the bereaved parents with premorbidity, and 22% of the bereaved parents without premorbidity (7% of the non-bereaved, RR 2.3; 95% CI 1.4 to 3.6) scored 10 or more on PHQ-9. The statistically significant difference between bereaved and non-bereaved parents remained after adjusting for known risk-factors for depression.



Anxiety: Twenty percent of the bereaved parents with premorbidity (2% among the non-bereaved), and 6% among the bereaved parents without premorbidity (1% among the non-bereaved) scored 3 or more on GAD-2.


Anxiety (GAD-2) Bereaved and non-bereaved parents, with and without premorbidity

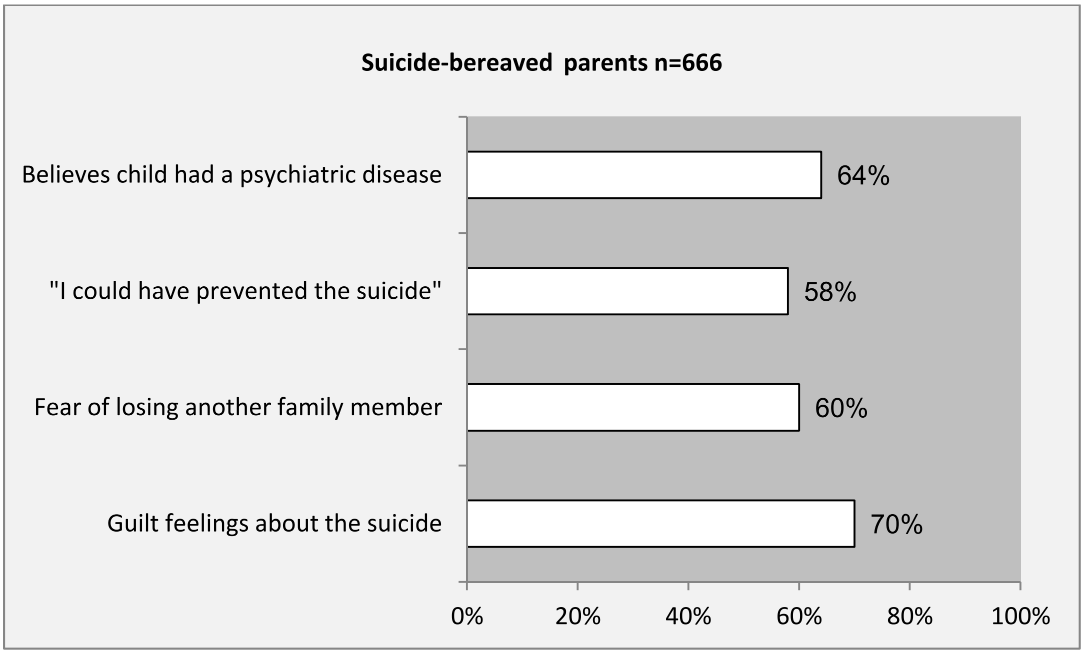
Alcohol consumption: Fourteen percent of the bereaved parents with premorbidity (12% of the non-bereaved), and 12% of the bereaved parents without premorbidity (7% among the non-bereaved without premorbidity) scored 8 or more on AUDIT.


Alchohol consumption (AUDIT) Bereaved and non-bereaved parents, with and without premorbidity

Other measures of psychological morbidity

In comparison with the non-bereaved parents, the bereaved parents showed a higher prevalence of psychological morbidity in all outcomes, for which every difference except harmful alcohol consumption and none-to-low physical health was statistically significant. We found the risk of feelings of guilt (without a specified cause) to be more than six times higher among the bereaved parents, and the risk of fear of next-of-kin's death about four times higher. Among the bereaved, 457 of 651 (70%) reported feelings of guilt for the child's death and 372 of 642 (58%) believed that they could have prevented the suicide.

One out of four, 164 of 666 (25%) reported that their child had self-harmed and 150 of 666 (23%) that their child had tried to commit suicide during the year prior to the suicide. Seventy-nine of 666 (12%) also reported that their child had been in contact with the healthcare system several times as a result of suicide-attempts during the year prior to the suicide. One out of two, 339 of 666 (51%) were anxious over the child's psychological health and 294 of 666 (44%) had worried that their child might commit suicide during the month prior to the suicide. The suicide was perceived as somewhat expected by 259 of 666 (39%) of the parents and 424 of 666 (64%) believed that their child had suffered from a psychiatric disease such as depression, anxiety disorder, personality disorder, psychosis or substance abuse.



5.4.1.3 Overview - professional help

Two to five years after the son's or daughter's suicide,

- 639 of 666 (96%) parents thought that healthcare personnel should contact parents who have lost a child to suicide to offer information and support.
- 574 of 666 (86%) parents thought that health care personnel should contact the parents again if they had declined the offer during the first conversation.
- 600 of 666 (90%) parents suggested that the contact should be established within the month of the death.
- 399 of 666 (60%) parents answered that they had met a professional person after the death to discuss possible explanations to the child's death, 240 of 399 (60%) perceived this discussion as valuable.
- 595 of 666 (89%) parents believed that the opportunity to discuss possible explanations to the suicide should be offered.
- 359 of 666 (54%) parents answered that they had been offered the chance to speak with a professional during the year after the death, 290 of 359 (81%) participated and 268 of 290 (92%) perceived the conversation as valuable.
- 644 of 666 (98%) parents thought the healthcare system should offer a meeting with a professional during the year after a child's death.
- 95 of 666 (14%) parents received information about common grief-responses in connection to the death.
- 452 of 666 (68%) parents thought the information about common grief-responses should be given both verbally and in writing.

5.4.1.4 Overview - experiences of healthcare

Two to five years after the loss of the son or daughter, 200 of 654 (30%) parents reported that they, after the loss, had been negatively affected by what a professional had said or done. The majority (86%) of the parents that had been negatively affected reported that they still were being negatively affected by this, two to five years after the loss. Furthermore 293 of 666 (44%) reported that they had been positively affected by what a professional had done or said, and nearly all (93%) of them said they were still being positively affected by this even today.

5.5 Viewing the body (Paper IV)

Research on the assumed positive and negative psychological effects of viewing the body after a suicide loss is sparse and findings incongruent. We hypothesized that suicide-bereaved parents that viewed their child´s body in a formal setting seldom regretted the experience, and that viewing the body was associated with lower levels of psychological morbidity two to five years after the loss.

We asked the bereaved parents if they had viewed their dead child at:

- The emergency department or ward
- Hospital church
- Department of forensic medicine
- Funeral parlour

Defined as formal settings
in the questionnaires subsequent
questions

And 460 of 666 (69%) stated that they had viewed the body in at least one of the formal settings above, 202 (30%) that they had not, and four (<1%) did not respond to the questions. The question "Do you regret that you viewed your child after the death" was answered by 456 of the 460 parents that had viewed. Ten answered that they had not viewed the body. Of the remaining 446, 430 (96%) answered "No", 9 (2%) "Yes, little", 2 (<1%) "Yes, moderate" and, 5 (1%) "Yes, much". According to the written comments, several of the parents that regretted viewing the child had witnessed a decomposed body. Some of the ones that regretted viewing also wrote that they wished that they had been better prepared for the scene that met them. Regrets were significantly lower among those who had lost a son or daughter to a violent suicide than among those who had lost a son or daughter by poisoning (relative risk 0.19, 95 percent confidence interval 0.07 to 0.49).

The question "Do you wish that you had viewed your child after the death" was answered by 198 of the 202 parents that did not view the body in a formal setting. Thirty-nine answered that they had viewed the child. Of the remaining 159, 99 (62%) answered "No", 25 (16%) "Yes, little", 11 (7%) "Yes, moderate" and, 24 (15%) "Yes, much". According to the written comments several of the ones that did not view the body had been advised by the officials not to do so, since the body was severely damaged or had started to decompose.

We also asked whether the parents thought that the viewing was performed in a dignified way and 19 (4%) answered “No”, 21 (5%) “Yes, a little”, 63 (14%) “Yes, moderately” and 352 (77%) “Yes, much” on at least one question regarding if the viewing was performed during dignified circumstances and five (1%) did not answer the question (table 8).

No/tot no (%)	**No**	**Yes**[1]	**Missing**
Did you view your child at the **Hospital (ED or ward)**	517/666 (77.6)	140/666 (21.0)	9/666 (1.4)
If yes, was it during dignified circumstances	8/140 (5.7)	130/140 (92.8)	2/140 (1.4)
Did you view your child at the **Hospital church**	431/666 (64.7)	227/666 (34.1)	8/666 (1.2)
If yes, was it during dignified circumstances	7/227 (3.1)	217/227 (95.6)	3/227 (1.3)
Did you view your child at the **Dep. of forensic medicine**	555/666 (83.3)	98/666 (14.7)	13/666 (2.0)
If yes, was it during dignified circumstances	2/98 (2.0)	92/98 (93.9)	4/98 (4.1)
Did you view your child at the **Funeral parlour**	448/666 (67.3)	209/666 (31.4)	9/666 (1.4)
If yes, was it during dignified circumstances	5/209 (2.4)	196/209 (93.8)	8/209 (3.8)
Did you view your child at the **Any of the above**	202/666 (30.3)	460/666 (69.1)	4/666 (0.6)
If yes, was it during dignified Circumstances[2]	19/460 (4.1)	436/460 (94.8)	5/460 (1.1)

Table 9. Viewing the body in a formal setting. Viewing also includes viewing the contour of the body or part of the body.[1]The summarised value of “yes, a little; yes, moderate; yes, much”[2] The most unfavourable value ranging from “no; yes, a little; yes, moderate; yes, much” at any of the formal settings

The viewing was associated with a statistically higher risk of reliving the child's death through nightmares (relative risk 1.61, 95% CI 1.13 to 2.32) and intrusive memories (relative risk 1.20, 95% CI 1.04 to 1.38) but not with anxiety (relative risk 1.02, 95% CI 0.74 to 1.40) and depression (relative risk 1.25, 95% CI 0.85 to 1.83) (see paper IV for further details).

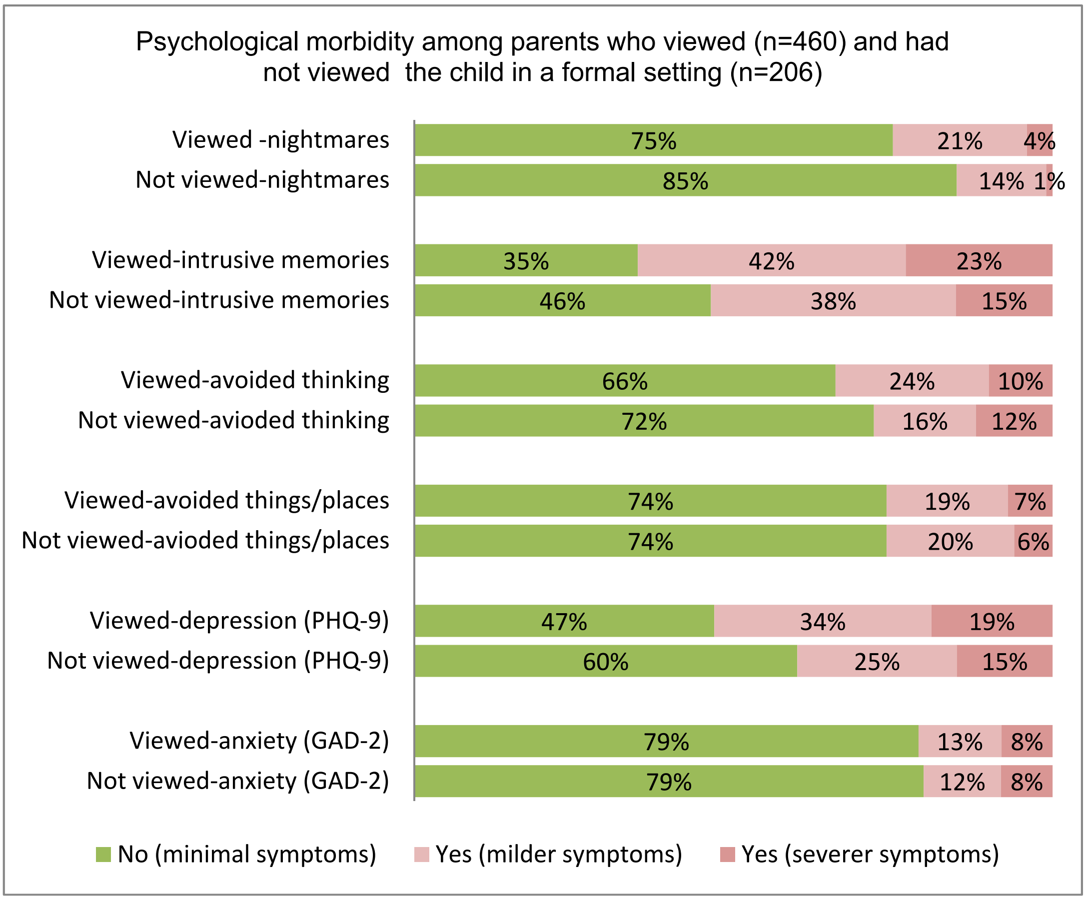


Figure 10. Two to five years following up: psychological morbidity among parents that viewed the body of their deceaced child and did not view the body
"No (minimal symptoms)"="No"; score 0-4 on PHQ-9; score 0-1 on GAD-2
"Yes (milder symptoms)"="Yes occasionally"; score 5-9 on PHQ-9; score 2 on GAD-2
"Yes (severer symptoms)"="At least one a week"; score ≥10 on PHQ-9; score ≥ 3on GAD-2

	Suicide-bereaved parents	
Circumstances related to the suicide	Viewed in a formal setting No./total no. (%)	Did not view in a formal setting No./total no. (%)
How did your child commit suicide		
Poisoning	64/101 (63.4)	37/101 (36.6)
Hanging, strangulation, suffocation	266/345 (77.1)	79/345 (22.9)
Drowning	3/8 (37.5)	5/8 (62.5)
In front of moving vehicles	37/81 (45.7)	44/81 (54.3)
Jumping from a height	36/46 (78.3)	10/46 (21.7)
By firearm discharge	29/45 (64.4)	16/45 (35.6)
Cutting, stabbing	5/6 (83.3)	1/6 (16.7)
By car-crash	6/10 (60.0)	4/10 (40.0)
Other way	5/8 (62.5)	3/8 (37.5)
How did you know that your child was deceased		
Found dead child	86/109 (78.9)	23/109 (21.1)
Saw dead child at site but not as first person	23/32 (71.9)	9/32 (28.1)
Notified in person	207/297 (69.7)	90/297 (30.3)
Notified by telephone	108/179 (60.3)	71/179 (39.7)
Notified in writing	2/2 (100)	0/2 (0)
Other way[1]	32/40 (80)	8/40 (20)
Did you receive the death notice from a professional person		
No	201/292 (68.8)	91/292 (31.2)
Yes	251/358 (70.1)	107/358 (29.9)
If yes, did the person come to your home		
No	95/139 (68.3)	44/139 (31.7)
Yes	186/268 (69.4)	82/268 (30.6)
If yes, did the person stay as long as you wanted		
No, too short	32/45 (71.1)	13/45 (28.9)
No, too long	4/5 (80.0)	1/5 (20.0)
Yes	176/257 (68.5)	81/257 (31.5)
Where you informed that your child died by suicide at the time of the death notice		
No	52/68 (76.5)	16/68 (23.5)
Yes	339/508 (66.7)	169/508 (33.3)
Was the death notice given in a dignified way		
No	61/79 (77.2)	18/79 (22.8)
Yes, a little	51/75 (68.0)	24/75 (32.0)
Yes, moderate	78/112 (69.6)	34/112 (30.4)
Yes, much	144/225 (64.0)	81/225 (36.0)
Where you prepared that your child might have committed suicide, when you received the notice		
No	261/361 (72.3)	100/361 (27.7)
Yes, a little	64/88 (72.7)	24/88 (27.3)
Yes, moderate	22/33 (66.7)	11/33 (33.3)
Yes, much	83/138 (60.1)	55/138 (39.9)

[1] Of the 40 parents that stated “Other way” 17 wrote that they were present at the time of death; 11 at the hospital and 6 had witnessed the suicide, 21 parents wrote that they received the death notice from someone else and two did not comment on the question.

Table 10. Circumstances related to the suicide and the viewing.

6 DISCUSSION

6.1 Methodological considerations

The validity of a study depends on the presence of errors. All studies are affected by randomly or systematically induced errors, to a various degree. The errors can be divided into random errors (chance) and systematic errors (bias). The “perfect study” without errors is hard to design even when using one’s wildest imagination. As researchers we want to find a perfectly true association between an exposure (a real-life event) and an outcome (a real-life problem). Even if the “perfect study” only exists in theory; picturing the perfect study design, as well as possible errors is useful when planning a real-life study. We used Steinecks Hierarchal step-model to identify possible threats to the validity throughout the research process. According to the model each new phase of the research process introduces a novel and a special source of systematic error. In figure 10 below and in this chapter we describe how a real-life study like ours step-by step departs from “the perfect study” into the calculated effect measure. The main sources of systematic errors that might threaten the validity of our study are divided into: confounding, misclassification, misrepresentation and analytical errors due to adjustments.

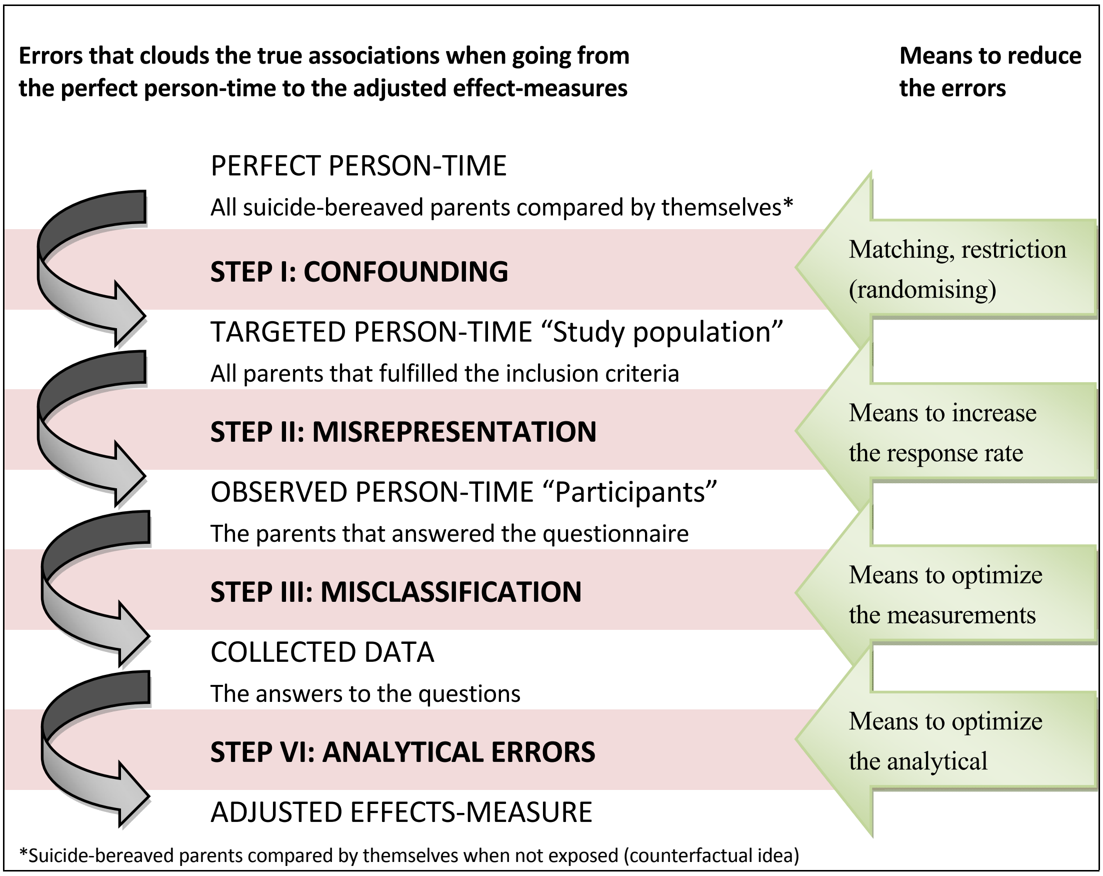
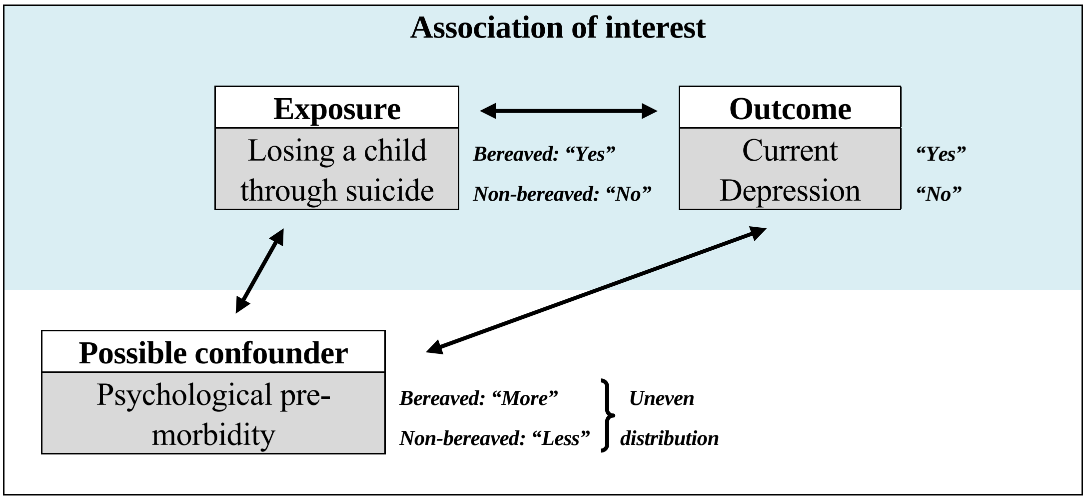


Figure 11. The figure above is a modified version of Gunnar Steineck’s hierarchal step-model for causation of bias

6.1.1 Confounding (Step I)

To act as a confounder the factor must: a) be a true risk factor for the outcome in itself and b) be associated with, but not affected by, the exposure. A confounding factor causes an over- or underestimation of the true association between the exposure and the outcome and becomes a serious problem if there is an uneven distribution of the confounding factor between the groups of comparison. We therefore strived to make the groups of comparison as equal as possible except for the exposure factor. Since randomization was not feasible in our study we had to use other means to reduce the risk of errors due to confounding. When planning the study, restriction and matching are two ways of handling this problem. Possible confounders may also be handled during data analysis for example by stratification and statistical adjustments (paper III, IV). Identifying and including questions on possible confounders in the questionnaire is therefore important and was emphasised in our preparatory study (paper I). Unfortunately we did not have the means to do a careful preparatory study and data collection using other languages than Swedish. Different cultures and experiences may however introduce confounding factors. Besides ethical reasons (see ethical considerations), this was one of the reasons why we restricted the participation to only include participants born in one of the Nordic countries. Furthermore we matched the parents that had lost a child and the parents that had not lost a child on: marital status, age, gender, living area, number of children and index child (a child born the same year as the deceased child). The figure shows an example of a possible confounder:



Psychological premorbidity has previously been pointed out as an important confounder for mental disorders like depression in the aftermath of a suicide loss, and for this reason we chose to measure the prevalence of psychological premorbidity among the suicide-bereaved and the non-bereaved parents. We found that the overall prevalence of psychological premorbidity did not differ across the groups we studied, suggesting that premorbidity is not confounding this association. However we do not know if the severity of the premorbidity differed between the groups and we therefore chose to stratify according to psychological premorbidity in our analyses (paper III).

6.1.2 Misrepresentation (Step II)

When the non-participants differ from the participants it could lead to errors, especially if the association between exposure and outcome is different among non-participants compared to participants (difference between the targeted person-time and the studied person-time). A high participation rate is therefore critical in this kind of study. We received an unusually high participation rate considering the study-population and the study-design. Nevertheless 27% did not participate and we do not have data to investigate whether they differ from the participants regarding for example psychological morbidity. Among the non-participants in our study, 18% of the bereaved and 5% of the non-bereaved explained their non-participation with psychological distress or ill-health but we do not know anything about the group that did not comment on their non-participation. It is likely that completing an extensive questionnaire with sensitive questions might be extra challenging for a person with psychological morbidity. Based on this notion as well as previous research, psychological morbidity might be more prevalent among the non-participants; probably leading to an underestimation of the symptom. On the other hand, the motivation for research participation might be higher among those with psychological ill-health.

Several factors are known to increase as well as decrease the response to postal questionnaires. For example sensitive questions and extensive questionnaires are known to decrease the participation rate. In addition we made it easy to decline and were careful not to persuade anyone to participate or to continue participation (see data collection). Notably 85% of the suicide-bereaved and 82% of the non-bereaved parents agreed to participate at first but in the end 73% bereaved 74% non-bereaved returned their answered questionnaires. A less extensive questionnaire might have reduced the drop-out; and this was mentioned in the motivations for non-participation. However there is also a risk that a short questionnaire would have been perceived as too shallow and one-sided by some respondents. Unconditional monetary incentives (personal or to organisations) are known to increase the response to postal questionnaires. Furthermore WHOs “Standards and operational guidance for ethics review of health-related research with human participants” advocate compensations off costs associated with the research (including compensation for consumed time). Save for that the compensations must not be so large so individuals consent to participate against their better judgement. Despite this, ethical committees are sometimes reluctant to approve monetary incentives in research that involves vulnerable persons, since the payment might be thought of as coercion; however this possible effect is yet to be carefully studied. Thus no compensation was given in this study.

6.1.3 Misclassification (Step III)

Misclassification mainly refers to errors that occur when the person is wrongly categorised, for example when a depressed person is classified as non-depressed. Errors that might lead to misclassification can be related to the researcher, the respondent and to the measurement itself. Misclassification becomes a serious problem when the error is unequally distributed across groups of comparison. To reduce these kinds of errors, we used our preparatory study and put special emphasis on investigating if the respondents understood the questions as we intended them to be understood and whether they were able and willing to answer the questions truthfully.

Errors related to the researchers-preparatory-study

There is always a risk that the researcher affects the responses when the study is not double-blinded. We had our pre-understanding and working hypotheses from previous research and clinical experience before the interviews. During the in-depth interviews we therefore strived to interfere with questions as little as possible. Despite this, the researchers' interference and choices may affect the findings and thus, the questions included in the questionnaire. For example, the interview started with the researcher encouraging the parent to tell about the child. In this way the informants narrated their experiences chronologically and when they came to telling about how they felt today, their energy had decreased. The exploration of different psychological outcomes was therefore not optimised during the interviews. Furthermore most of the approached informants had a good social network, which might have affected their experiences. We tried to recruit participants by an advertisement in a free weekly newspaper reaching more than 30 000 households, but only one parent answered.

Interviewer-induced misclassification might also occur during the qualitative analysis and to reduce this risk we chose to stay close to the informants' statements and presented all quotes as well as the chosen quotes (later questions) when discussing within the research team. We also ensured that we had not forgotten any essential issues by asking external experts to view the hypotheses and the questionnaire draft. We also asked the suicide-bereaved parents in the preparatory study (n=46) if they had missed any essential questions and found that by and large everyone thought that the questionnaire covered the essentials with the exception of the questions about the siblings (paper I). In summary we believe that our questionnaire captures the essential questions need to cover the aim of our study. There are probably important outcomes related to long-term psychological morbidity that we have missed including in the questionnaire but this is not likely to compromise the outcomes (and findings) we studied. However, in the light of this discussion, in paper IV we concluded "We found no support for the position that viewing the body in a formal setting had a positive effect on the psychological outcomes, two to five years after the loss" but we could have been more explicit if we had written "We found no support for the position that viewing the body in a formal setting had a positive effect on the psychological outcomes **that we studied**, two to five years after the loss".

Errors related to the researchers-the population based survey
Due to the risk of information-bias, one may argue that the researchers who know the hypotheses should not have contact with the respondents for example by answering the respondents' questions about the study. On the other hand, previous studies including suicide-bereaved persons suggest that the contact should be done by a person with experience in supporting persons in crisis. We also needed a person that could be available at any time if crisis support was needed. In this study we were two callers and the initial phone-calls were equally distributed between us. To treat all informants alike (aware of not affecting the answers) and for ethical reasons we strived to follow our step by step approach when calling (paper II). Despite this we cannot rule out that the contact might have affected some respondent's answers. However considering the handful of informants that might have been affected and the large number of participants this should not be a problem in our study. Misclassification may also be introduced during data entering; we therefore carefully prepared and performed the task related to data entering and continually tested the accuracy (see data entering).

Errors related to the "respondents"
Several factors affect the individual's ability and willingness to answer the questions truthfully. We enabled the respondents to answer the questionnaire anonymously which reduces the risk of response bias as well as interview bias. Some persons might for example be reluctant to be registered as having psychiatric problems (paper III) while others might be hesitant to tell about negative experiences related to their research participation (paper II). Blame and stigma (from oneself as well as from others) are common in the aftermath of a suicide loss; the idea that a parent's psychological morbidity might have affected the parenting might therefore lead to underreporting of psychological premorbidity (paper IV).

During the preparatory study we investigated if there were any questions that the respondents did not want to answer and some were identified (see preparatory study). We also assessed if the respondents were able to recall the events we asked for. For example no one doubted if and where they had seen the body of their dead child and no one had difficulty in answering the question whether the "viewing was undertaken during dignified circumstances" (paper IV). However, although the respondents had no problem of recalling this event the memories might be altered by time as well by their current psychological status. It might be easier for depressed persons to recall negative events than non-depressed persons, but this cannot explain our findings in paper IV, since depression was reported by 19% of the persons that had viewed the body and only 4% of them reported experiences of an "unworthy viewing". Some memories might also be affected by defence mechanisms for example a too painful memory might be suppressed or replaced by a less painful one.

Errors related to the measurements

Our main outcomes were measured with scales proven to have good psychometric values in similar populations. Modification of the scale may however affect the precision of the measurement. An altered precision is largely a concern when comparisons are being made across studies but is not likely to be a problem when comparing groups within a study (using the same measurement). We believe that the minor modifications we made might have increased the number of respondents answering the depression and anxiety scales. We estimated the changes of the calculated scores to be minor if any and our results were congruent with results from similar studies (IV). We also found a high consistency when comparing the scores derived from the psychometric scales against our single-item questions. For example, all bereaved individuals (n=139) who answered "no" to the question "Have you felt low or depressed during the last month" scored nine or lower on PHQ-9 and 84% who answered "yes, 6-7 days a week" scored ≥10 on PHQ-9.

When possible, we compared the answers from the questionnaire with the group-level data that we got from the registers. This was done with the socio-demographic variables and bereavement status and we found a high consistency. We also compared answers between questions that were expected to produce similar results. Infrequently we found questions with inconsistent results and these were excluded from the analyses. For example, an unreasonably high prevalence of parents answered that they had lost a parent or sibling during their upbringing (before 20 years of age). Comparing with prevalence's from statistic Sweden we concluded that some of the bereaved and non-bereaved parents must have misinterpreted the question. This was also our conclusion after comparing the answers against the detailed questions about losing a family member to suicide that we also had in the questionnaire. However for most study specific questions we had no objective comparison. There is of course a possibility that some persons do not answer the question truthfully but we estimated that this should be a minor problem, not large enough to affect the effect measure.

When comparing a group of people that has experienced a traumatising and life changing event with a group that does not have this experience one must always consider that the event may have changed their frames of reference (response shift). For example, when answering the question *"Have you felt down or depressed, during the last month?"* the parent compares how he or she has felt during the past month against how he or she has felt before that. In this way, parents that have experienced the worst of sorrows may rate their current sorrow as lesser than the ones that have not experienced great sorrow. This was one of the reasons why we chose to measure our single-item questions with prevalence scales over visual digital scales. In the light of this discussion one may think that the prevalence of for example depression might be underestimated among the bereaved parents. However, we have not yet studied the bereaved person's perception of depression in relation to their grief-related symptoms and we do not know their ability to disentangle these symptoms from each other. Also, the experience of losing a child may "open the eyes" for positive things that previously have gone unnoticed.

6.1.4 Analytical Errors (Step IV)

Every time information is transferred into another medium or handled, new errors may be introduced. We involved a statistician/epidemiologist early in the research process in order to reduce errors that arise in the process of "data collection ↔ collected data ↔ measurements". During this step we try to reduce errors from the previous steps by stratifying and adjusting the effect measures (relative risks and odds ratios). We identified possible exposures, outcomes, modifiers and confounders when we created the hypotheses in the preparatory study (paper I). We started the analyses by dichotomizing the values derived from the psychometric scales and used log-binomial regression to calculate relative risks. Next step was to asses if the associations could be explained by a confounding factor. We performed a variable selection among the possible confounders, using logistic regression with forward selection in order to identify those variables most strongly related to the main outcomes in each group (see selection in statistical analysis). We wanted to maximise the possibility of finding other variables that could potentially disprove the assumed effect and used a liberal inclusion criterion allowing variables up to the 15% significance level entry.

In our tables we present the effect measure unadjusted, adjusted with one variable at a time and adjusted for multiple variables (for selection procedures see papers). The effect measure was similar after adjustments which suggest that none of the potential confounders we had considered could explain our main finding. However we cannot exclude the possible influence of unknown and unmeasured variables on the effect measures. Moreover one may argue that we could have used several models for our multivariable selection as well as other statistical tests. However we estimate that different analyses would only have minor effects on our effect measure, thus not being enough to change the data supporting our main findings (paper II, IV). When possible we chose to present our results in terms of relative risks [RR] in preference to odds ratios [OR]. The reason for this is that we believe that RR are easier than OR to comprehend, which is a concern for us as we believe our results may be important to clinicians who are not always familiar with statistical methodology. A prevalence of 30% versus 10% will for example give a relative risk of 3.0, but an odds ratio of 3.9, and if this OR was to be presented by itself it might be misinterpreted as reflecting a near fourfold higher occurrence while the occurrence is actually threefold. Dichotomising the data instead of using all the variables may lead to loss of statistical power and somewhat altered results. We therefore chose to test the association between the level of exposure and the levels of psychological outcomes using Wilcoxon-Mann-Whitney's test (Paper III, IV).

6.1.5 Generalisability

We consider our results to be trustworthy in the population that we studied. We also believe that our results make a valuable contribution to the existing knowledge in the field. For ethical and methodological reasons we could not include all parents that had lost a son or daughter in this survey (see ethical considerations). However, some of the results from our study are less affected by for example time and place and might therefore be as trustworthy in other populations and settings. We have described our research process and our data in detail in order to enable other researchers and clinicians to decide whether our data can be applicable for them in their setting.

6.2 Comments on findings

The quotation below is retrieved from an information folder produced by the Swedish suicide survivors group (SPES) (http://spes.se)

”Suddenly the world falls apart. The worst that can happen, that only happens to others, has happened to us. In one blow life is changed never to be the same again”

One of the worst things that can happen to a human being is the death of a loved one. Even the thought of death and suicide is frightening, so frightening that we tend to shield ourselves. Distancing oneself is one way of doing this, for example by thinking “this does not apply to me”, or “this only happen to other families - families with problems”[14,42,43]. This distancing can add to the stigmatization that already surrounds death by suicide. Another way of shielding oneself is to avoid frightening things; this might be why we sometimes fail to ask about suicidality or avoid facing a suicide-bereaved person. Avoidance might present itself in different ways, for example: surrounding people may act like the lost son or daughter never existed; ethical committee members may oppose a study without a thorough investigation or with non-scientific arguments, and insecure care providers may find practical excuses for not wanting to show the dead body. Fear of awakening feelings and memories in the afflicted person is another explanation to avoidance. Talking about the lost person may indeed raise painful feelings like sadness. However, bereaved parents often describe grief-related pain as something they experience in their daily life without particular remembrance. Furthermore nothing indicates that feelings of sadness should be harmful and that things that evoke feelings thus should be avoided.

Sometimes the fear of harming someone leads to overprotection and wrongful exclusion[14,15]. The parents might be hindered in making their own decisions for example regarding whether they want to participate in research or not and whether they want to view the body of their deceased child. Throughout our study, many bereaved parents have shared experiences of avoidance and distancing, similar to the examples above. Personal fears expressed by officials in government agencies have also seriously delayed our study. It may be that some of our most important findings in this thesis are the ones that challenge the ancient fears and taboos that persistently surround suicide (and suicide-bereavement), since they continue to be governed by some professionals as well as by laymen.

“Suicide is a whispered word, inappropriate for polite company. Family and friends often pretend they do not hear the word’s dread sound even when it is uttered. For suicide is a taboo subject that stigmatizes not only the victim but the survivors as well.” Earl A. Grollman[100], 1998, p 1.

Throughout our study, the suicide-bereaved parents expressed their need and gratitude over the possibility given them to share their experiences related to their loss due to suicide. The parents also emphasised the need for offering formalised help to families touched by suicide. Our findings support previous research findings; that it is possible to conduct an extensive survey in the aftermath of losing a child to suicide (paper I). Our findings also support the notion, given that the study design is ethically and methodologically sound, that the benefits of contact and participation outnumber the risks (paper II). Furthermore the high prevalence of psychiatric morbidity, two to five years after the loss, highlights the need for development of professional interventions to reduce the suffering among suicide-bereaved parents (paper III). By and large everyone that had viewed their deceased child in a formal setting did not regret the viewing. Of equal importance, more than half of those who did not view the body did not wish that they had. The findings from our fourth study also shows that more research is needed to guide professional interventions (paper IV).

6.2.1 Paper I and II

6.2.1.1 Experiences of contact

Most parents that declined participation did so in a friendly manner, without hesitation or signs of distress. Several parents also expressed gratitude over the study even if they declined participation. Our impression that most parents did not have a problem with either declining or accepting participation has also been noted in other studies[14,24]. We got no indication that anyone was negatively affected in the long term by the contact. Nevertheless, some parents might have been temporarily distressed without expressing this distress during the phone call. In all, eight persons seemed to have been offended by the contact per se. Two persons were initially shocked and distressed that the cause of death could be attributed to suicide but during the follow-up the distress ceased and they expressed gratitude over being contacted was expressed. The remaining six persons were not contacted again. We do not know whether they were bereaved or not, nor if the distress was solely a result of the contact. Part of the distress may, for example, have been caused by other factors like ongoing ill-health or environmental stressors. Additional stress caused by the contact might be negative in the short run but also beneficial in a longer perspective since bringing problems to the surface and talking about them might help the afflicted person in dealing with underlying problems. Importantly several of the participants and non-participants received help as a result of the contact. Population-based surveys are common but we have not found any reports on how the study population perceived being contacted. We do not believe that our findings are unique for our study – a belief supported by information from other researchers and research assistants.

6.2.1.2 *Experiences of participation*

A significant minority wrote that they had been temporarily negatively affected by their participation of which two parents, one bereaved and one not, said that they thought that the negative effect might last. Compilation of trauma-related studies suggests that a minority of participants become distressed when being interviewed or when filling out a questionnaire and that the distress quickly diminishes[14,15,23-28]. However, the long-term psychological effects of research participation have not been carefully studied[14,15]. Recalling a traumatic event by telling or writing about it or by answering questions might raise the level of short-term distress, but it is unlikely to cause re-traumatization or long-term harm. The temporary distress must, however, be acknowledged[14,15]. We believe that our study design that thoroughly considered every detail of the written and personal contacts reduced the number of distressed persons. We also believe including deaths due to "uncertain" causes (ICD-10 code Y10–34) would have resulted in more parents becoming distressed. We believe that the personal telephone call and being able to communicate in Swedish were important in making it possible to provide information and support.

In contrast with the sparse expressions of negative experiences, positive experiences were widely expressed. Gratitude for the opportunity to relate experiences and for the interest shown by us may be related to the reduction in avoidance and distancing commonly described in the aftermath of the suicidal loss. Several parents wrote that they perceived working through the memories and feelings raised by answering the questionnaire as being helpful. At the same time, "painful memories" and "feelings of sadness" were the most common motivation to being negatively affected or regretting participation. This shows the complexity of the questions. On one hand, the respondents are the only ones that can put this question in a context of their whole situation, but on the other hand the wording "negative or positive" might be misleading. The majority of the bereaved parents that reported being temporarily negatively affected referred to painful memories and feelings of sadness in their written comments. However, several respondents also wrote that these feelings were not necessarily bad for them and more than half of those who reported being negatively affected also stated that they had been positively affected by their participation. There is a risk that respondents use different evaluation criteria when they answer.

6.2.2 Paper III

As the first publications resulting from our research, the papers in this thesis are wide-ranging providing a frame-work for future papers on more specific outcomes. In our third paper, we present an over-view of psychological morbidity among bereaved and non-bereaved parents. We could have focused on bereavement-related depression, investigating different risk factors such as sex and age more thoroughly. However, when researchers talk about bereavement-related depression, questions about: *"depression in the general population", "psychological premorbidity" and "other symptoms of psychological morbidity"* often arise. We therefore chose to present information on the prevalence of a wide range of psychological outcomes in this first paper (see future perspectives).

6.2.2.1 Comparison and interpretations

There are some studies investigating psychological premorbidity (direct or indirect) among parents bereaved by suicide, although the issue is yet to be studied carefully. Presenting findings from existing studies may increase our understanding, although comparisons across studies might be more or less futile due to different study-populations, follow-up times and measurements. We therefore limit our comparisons to broader general findings. Some of our results regarding psychological premorbidity also need further investigation. We found no statistically significant difference between the prevalence of psychological premorbidity between the bereaved and non-bereaved parents. However, our questions do not include the intensity or duration of the premorbidity. Although our questions about psychological premorbidity were restricted to include only "diagnoses or treatments prescribed by a physician", the premorbidity might range from "mild over-going symptoms" to "psychiatric diseases with severe and lifelong affliction". The bereaved parents had a slightly higher prevalence of the types of premorbidity that were addressed in each of the four questions asked, which might reflect a more severe affliction. However, of this we can only speculate. This potential confounder could be of concern when comparing across the groups with premorbidity but not when comparing across the groups without premorbidity since these groups should be homogenous on this subject under study (see method discussion).

6.2.2.2 Suicide-bereavement and risk of depression

We found that the bereaved parents had a more than twofold increased risk of being depressed in comparison with the non-bereaved parents, and the risk was found both among those with premorbidity and those without. Most register studies that we found on bereavement-related depression have excluded parents with previous psychological morbidity. There are for example two large register-based studies from Denmark[2,3] showing a twofold risk of being first-time admitted for depression in the aftermath of a child's suicide (paper III). We found one case-control study investigating suicide-bereavement and risk of depression that was of use for comparing our results regarding the parents with premorbidity[101]. In Bolton and co-workers'[101] study, 206 of 1415 (15%) suicide-bereaved parents were diagnosed with depression two years before their loss and 431 of 1415 (30%) were diagnosed with depression two years after their loss – resulting in a twofold risk.

6.2.2.3 Prevalence of psychological premorbidity

In our study, 14% of the bereaved parents (14% of the non-bereaved) had “received treatment and/or a diagnosis of psychological morbidity”, more than 10 years earlier. In Stenager and Qins[102] population-based study (4,142 suicide cases and matched controls) 6% of the suicide-bereaved parents (3% of the non-bereaved) had been admitted to a psychiatric hospital ten years prior to the suicide. In Bolton and co-workers study[101], 28% of the suicide-bereaved parents (n=1415) were diagnosed with a mental disorder two years prior to the suicide. Bolton and co-workers also found that parents bereaved through suicide had a slightly higher level of depression two years prior to the loss in comparison with the parents bereaved through a motor vehicle crash (n=1132). One explanation for the elevated premorbidity may be that the suicide-bereaved parents had a higher level of psychological premorbidity due to genetic and environmental factors. In the study by Bolton and co-workers, as many as 28% of the suicide-bereaved had received a psychiatric diagnosis before the loss. However, when measuring psychological premorbidity only two years prior to the suicide (in comparison with 10 years prior) part of the increase might be stress-related symptoms due to parenting a suicidal child rather than being related to a history of psychological premorbidity.

In our study, one out of four of the suicide-bereaved parents had experienced that their child self-harmed or had tried to commit suicide during the year prior to the suicide. During the interviews, several parents told about the immense stress that they had lived under (sometimes for several years) prior the suicide. Several told us of their suffering together with the child throughout his or her struggles (psychological, alienation, physical pain…) and about their fears of finding the child injured or lifeless. Some parents also said that they had lived under the constant stress that their child would hurt another family member under the influence of a psychosis.

”During this time, when the phone called, it was like my heart stopped every time and it was horrible. I was always afraid that something had happened. And it did happen a lot of things -she cut her wrists, she cut her throat, she threw herself in the lake, she did a lot of things” A mother who lost her daughter

”And then, the last week, then I was really worried. And I said to my wife, what shall we do? But my wife who had been ever so worried for seven years… was not worried at all this time” A Father who lost his son

”…it was this severe psychosis that made everything awful. I searched the drawers, I had to hide all knives, I had to make sure that nothing dangerous was in the way” A mother who lost her son

”…I was nervous and lived under continuous fear, all the time... I had to go to the store - to leave him alone, I was horrified. One time when I came home he was gone and right away I became like this [showing how her hands was trembling] A mother who had lost her son

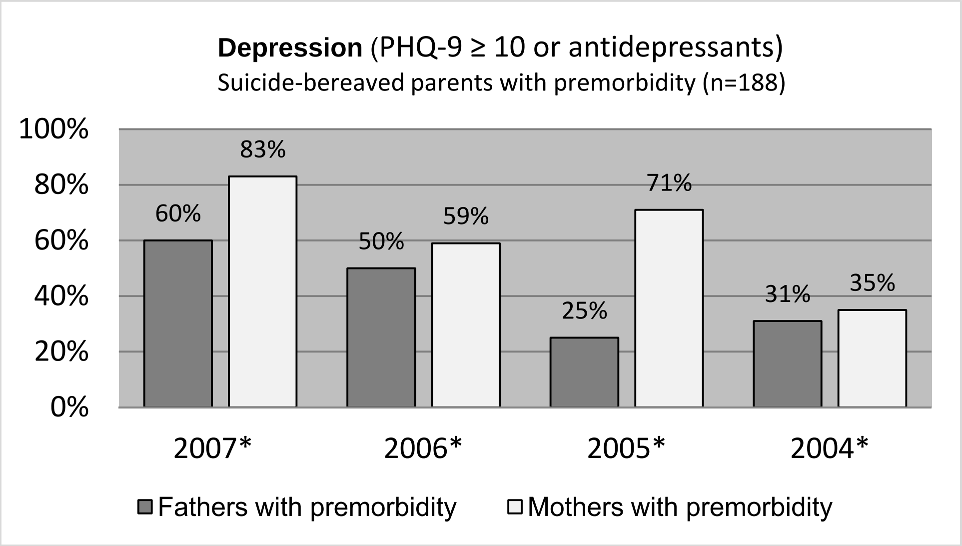
6.2.2.4 Prevalence of current psychological morbidity

We found that 25% of the bereaved parents (9% of the non-bereaved) were currently taking antidepressants or were moderately to severely depressed two to five years after the loss. Our results coincide with Bolton and co-workers[101] findings based on the in-patient registers where 31% of the suicide-bereaved parents (10% of the non-bereaved) were diagnosed with depression two years after the loss. As expected the highest prevalence of depression was found among bereaved mothers.

It is noteworthy that 62% of the bereaved mothers with psychological premorbidity (and 42% of the fathers) were moderately to severely depressed and/or were currently taking antidepressants, two to five years after the loss. The highest prevalence was found among those who had lost their child two years earlier but remained high also after five years had passed. We expected decreased psychological morbidity along with increased time since loss but this was not evident in our data, although this needs to be studied further. It is, however, evident that we had a too short follow-up time to study when and if the bereaved parents’ (with and without psychological premorbidity) level of psychological morbidity ever might reach the non-bereaved parents’ levels. In Kreicbergs and co-workers’ population-based survey[20] on parents that had lost a child to cancer (see background) it took seven to nine years until the bereaved parents mental health status reached the level of the normal population.

Fatigue, concentration problems, loss of interest or other symptoms related to psychological morbidity might pose hindrances to answering an extensive questionnaire. There might therefore be an association between non-response and psychological morbidity. Although most non-respondents gave no reason for ending their participation, the bereaved more often spoke about psychological ill-health. The bereaved parents’ prevalence of psychological morbidity might therefore even be higher than reported (paper II).

Several parents (64%) believed that their child had suffered from a psychiatric disease such as depression, anxiety disorder, personality disorder, psychosis or substance abuse. Despite this, guilt over the child’s death was common (70%) and more than half of the parents (58%) believed that they could have prevented the suicide. Numerous parents (60%) also regularly feared the death of another family member.



*Year of loss (two to five years after the loss).

During the interviews and the phone calls several parents described how they had struggled to help their child who suffered from severe psychiatric symptoms (the healthcare was often involved in the patients care without including the family) and how they perceived that they had failed. One mother, for example, told us about her daughter that sounded like she had been severely depressed with a history of several admissions to the psychiatric in-patient care and how she, the mother, had struggled to support her daughter in every possible way throughout the years. Despite this, she blamed herself and asked "what she had done wrong", "what she had done differently with this girl in comparison with her other children", "if the reason was that was that she had not breastfed her daughter", and so on. Other mothers talked about: leaving her "baby alone at the hospital", "medication taken during pregnancy", and "taking too much nitrous oxide during childbirth". Numerous parents also expressed guilt concerning that they (in hence sight) had not helped, listened or understood their child well enough. Feelings of guilt were also commonly described during the in-depth interviews.

"One suffers from enormous feeling of guilt. The first thing one thinks is "what have I done wrong". I should never have moved…and if I had not done that he might have been alive today… everyone says that it was not your fault, nevertheless one has to live with the guilt in some way…I can never be completely free from the guilt feelings, it is something one has to live with. I cannot say that I did not affect what happened; I cannot say this with certainty. There is a feeling of guilt - that if I had listened more thoroughly to what he had to say, then I might have…why did I put my own interests first and did not listen to him" A father that lost his son.

6.2.3 Paper IV

Discovering the body of the dead child is often assumed to have a negative effect on bereavement-outcome, while viewing the body in a formalised way is considered to be beneficial, although this is yet to be carefully studied[103]. During the in-depth interviews, several parents became emotional when they were talking about how they had found their lifeless son or daughter.

"When I went back, out from the house, I bumped into him; he was hanging in the apple tree. I took him down and shouted for my wife…I don't have nightmares, but it comes up in my thoughts. It is so etched in the brain; I can see exactly how it looked and what happened next. It will always be like that. On the whole, not one day passes without me thinking about it" A father who lost his son.

Several parents also expressed strong emotions when they told about viewing the body in a formal setting. One father expressed how he went to the hospital (after the death notice) because he had to make sure that it really was his son that had died. He also described the distress that he felt when he at first was denied to view his son by the healthcare personnel (they said that it could not be arranged that day). Other parents expressed gratitude for getting the opportunity to see their dead child and described the viewing as a memorable and valuable event.

"…I regret that I did not stay the whole night. Looking back it went to fast. I would have liked to have kept this last instance of closeness. I regret that I was scared and thought that it was horrible. How could/can I feel like that with my own child?"
A mother who lost her son

"After we had seen her it was chaos again, but it was an unbelievable stillness during that time. Everything was just hysterical but I just felt calm, an unbelievable calm and I felt like she was there with me. And her finger was a little bit dirty, but it was calm and unbelievable" A mother who lost her daughter

"I do not regret that I saw her, I had to see that it really was her" A father who lost his daughter

We hypothesised that suicide-bereaved parents that had viewed their child´s body in a formal setting seldom regretted the experience and found that by and large everyone that had viewed their child did not regret the viewing. Our findings coincide with Chapple and Ziebland study[103]. They found that relatives, bereaved through suicide or other traumatic deaths, who had chosen to view the body seldom regretted doing so. The findings were based on 80 in-depth interviews conducted in Great Britain between 2007 and 2008, four months to nine years after the loss. Like in their study we found that the parents often had numerous reasons for viewing the body. They mentioned the need for checking the identity, to care for the dead one and to say goodbye. A few persons stated that they regretted viewing of the body.

“I did not recognise him at all. It was a terrible shock to see his damaged face. That picture sometimes haunts me but I try not to remember…I wish they would have told me how he had changed. A father that lost his son”

In our study regrets were often followed by a comment that expressed shock over how their loved ones had changed. Providing information on what to expect has been stressed as an important element in reducing distress and regrets due to viewing the body after a traumatic death[103-105]. Interestingly, in our study, regrets were most often associated with death by poisoning rather than a violent method of suicide. The written comments also showed that the regrets mainly concerned witnessing a decomposed body rather than a body that was disfigured by the suicide. Possible explanations might be that after a violent death the relatives are better informed on what to expect and the body is more often shielded. The violently bereaved parents might also expect the worst. Our findings suggest that it is always important to inform the parents about the body’s appearance and about options for the viewing, whatever the mode of death. Health care personnel are often encouraged to carefully prepare the environment and the body before the viewing[104,106,107]. However, after an unverified suicide, cleaning the body may be delayed due to an ongoing police investigation. In our study, nearly everyone felt that the viewing took place during dignified circumstances, which suggests that the routines for viewing are efficient in Sweden and that complicating factors like an unprepared or damaged body might be accepted if the bereaved are carefully informed and supported during the viewing.

”…We wanted to see our child. She came to the clinic despite that it was Sunday and closed. In an incredible careful way she [the nurse] influenced us not to view our daughter. She was extremely empathic and respectful and we could not do otherwise than what she suggested. I still remember the feeling that she was honest and truthful in that she believe that we would be better off remembering her as she was when being alive”. A mother who lost her daughter

“The funeral director carefully told us where in the garage he was lying, what he was wearing and so on…and the police was fantastic and held my hand the whole time”. A mother who lost her son

The opportunity and decision to view or not to view the body is influenced by numerous factors, some of them known, others not. We have no quantitative data on whether the parents wanted and/or had the choice to view the body at the time of death. However, the written comments to the questions on this theme suggest similar to previous studies that the decision often was influenced by other persons and circumstances surrounding the body[103,108]. We also lack information about possible confounders related to different personality and coping strategies since existing inventories were considered too immense and the study-specific questions from the preparatory study imprecise. Although most of our questions concern how the parents feel today some answers may be affected by recall-induced problems. Some memories might also be affected by defence mechanisms for example a too painful memory might be suppressed or replaced by a less painful one.

There are also some who did not view who afterwards wished that they had. Chapple and Ziebland[103] showed that some respondents changed their mind regarding what they thought was best for them and that some, afterwards, were ambivalent about whether their decision was the best one. One explanation might be that these individuals may hold a belief that viewing is necessary for a healthy recovery, a view suggested by some respondents in our study as well as in the grief literature. Dublin and Sarnoff's review[104] from 1986 concludes that bereaved persons should be offered the opportunity to view the body but also stress that those who are reluctant or unwilling to do so must be supported by being told that their decision was the right one for them.

Our hypothesis that those who viewed the body in a formal setting would have lower levels of psychological morbidity than those who did not view was not supported by our findings. In contrast to our hypotheses, viewing was associated with a higher risk of reliving the child's death through nightmares and intrusive memories, although no differences between those who had viewed and those who did not view could be found regarding anxiety, depression or avoidance two to five years after the death. Research on the psychological effects of viewing the body after a suicide loss is sparse and this issue needs to be further explored.

We found two studies that investigated how confronting the body (at the scene of the death and at a formal setting) affected the level of grief difficulties among suicide-bereaved relatives[52,62]. Callahan's study[52] included 210 persons who had lost a family member or a close friend to suicide. The bereaved were all participants in suicide support groups and data were collected in Michigan (1989 to 1993) and Chicago (1995 to 1996) where the average elapsed time after loss was four years. Callahan hypothesized that "Not seeing the deceased's body at the funeral or memorial service" was associated with higher levels of grief as measured by the Grief Experience Questionnaire but found no impact on the overall level of grief. Feigelman and co-workers[62] studied a sub-group of 462 parents who had lost their son or daughter to suicide during a time span of less than a year to more than 10 years. An abbreviated version of the Grief Experience Questionnaire was used for the outcome measures and the parents were identified by suicide support groups in the USA. Figelman and co-workers [62] hypothesised that the suicide-bereaved who had viewed the body prior to the burial or cremation (n=189) would experience higher levels of grief difficulties than those who had not viewed the body prior to the burial or cremation (n=96) (the parents that had seen the body at the site of the death were not included in any of the groups) and found that those who had not viewed had a lower level of grief difficulties than those who had viewed. Our findings on the psychological effect of viewing the body in a formal setting are in line with Callahan[52] and Figelmans's[62] findings, thus challenging the notion that viewing the body is necessary for a healthy grief recovery.

7 CONCLUSIONS

Paper I-II We found that most parents perceived the research participation as something positive and that the contact was welcomed. The need for the research such as this was also strongly emphasised and supported by the findings. Our findings suggest, given that the study design is ethically and methodologically sound, that suicide-bereaved parents can be included in survey research if they choose to do so. It is, however, important to consider, prevent and care for any negative effects that might occur. In our study, a significant minority reported being temporary negatively affected by participation. There were also a few individuals that seemed to be upset by the contact. We believe that the number of distressed individuals was reduced to nearly a minimum and that our considerations described in the ethical protocol was the reason for this. We want to stress how important it is to take care of this significant minority. It is also important to note the significant number of non-participants and participants with severe psychological suffering that received help as a result of the contact (Paper III-IV).

Paper III We found that the bereaved parents had a more than twofold increased risk of being depressed in comparison with the non-bereaved parents; the risk was found both among those with premorbidity and those without. The same was found for the more than threefold higher risk of anxiety. In all, 25% of the bereaved parents were currently taking antidepressants or were moderately to severely depressed according to PHQ-9. The majority (86%) of the bereaved parents did not have psychological premorbidity when measured more than 10 years earlier. There was, however, a significant minority (14%) that had and it is noteworthy that 62% of the bereaved mothers with psychological premorbidity (and 42% of the fathers) were moderately to severely depressed and/or were currently taking antidepressants, two to five years after the loss. The highest prevalence was found among mothers with a history of premorbidity who had lost their child two years earlier (83%). A particularly high prevalence was also found among mothers (71%) four years after the loss, suggesting that the expected decreased psychological morbidity with increased time since loss was not evident.

Depression, as well as other forms of psychological morbidity, is associated with immense suffering. We believe that some of this suffering might be prevented or at least shortened with professional help. However, previous findings show that suicide-bereaved parents often do not have the strength to seek professional help in the aftermath of the suicide. In our study, when looking back, 96% of the suicide-bereaved parents thought that healthcare providers should contact parents that have lost a son or daughter to suicide. The majority of suicide-bereaved parents might not need professional help, but the contact could be one way of identifying those who do. We also believe that it is important to ask bereaved persons about previous psychological morbidity to identify individuals likely to need professional support. Another important aspect is that information about psychological ill-health and suicide might help to reduce feelings of guilt and to restore some of the lost faith in the health care system.

Paper IV. We found that by and large everyone that had viewed their deceased child in a formal setting did not regret doing so and that a majority of the parents that did not view their deceased child did not wish that they had. We found no support for the position that viewing the body in a formal setting had a positive effect on the psychological outcomes (that we measured), two to five years after the loss. Although no recommendations can be made, our findings suggest that the Swedish routines for viewing the body in a formal setting work satisfyingly. This routine specifies that it is the bereaved person that should be the one to give informed consent to view or not to view the body and that the officials may best support the parents in helping them to make their decision by carefully informing them about the child's appearance and how the viewing may be altered, for example, by shielding parts of the body. For parents that seek advice, the officials may also tell them that previous research suggests that most parents that want to see their child do not regret doing so and that viewing often is perceived as helpful although not necessary for a healthy recovery.

8 IMPLICATIONS

Our findings suggest that parents that have lost a son or daughter through suicide, two to five years earlier:

- May be included in research given that the research is methodologically and ethically sound
- Are capable of deciding whether to participate or not in this kind of research
- Want to be actively contacted and offered information and support from the healthcare system
- Can benefit from interventions to reduce psychiatric morbidity such as depression, especially those with increased vulnerability due to prior psychological morbidity
- May be asked about psychological premorbidity in order to reduce bereavement-related psychological morbidity through specific professional interventions such as treatment of depression
- May be given the opportunity to make an informed choice whether to view the body or not and this decision can be supported by the officials
- That seek advice concerning whether they should view the dead child or not may be told that previous research has shown that most parents that chose to view the body do not regret having done so and that they perceive the viewing as valuable
- May be advised that viewing does not seem to be necessary for a healthy recovery

Furthermore:

- Our ethical protocol for reducing distress during contact and research participation can be useful for researchers and ethics committee members when planning future research with individuals that may be vulnerable due to trauma-related experiences
- The high prevalence of psychological morbidity among suicide-bereaved parents highlights the need for development of clinical interventions and routines for supporting this group
- The knowledge that the majority of suicide-bereaved parents do not have psychological premorbidity is valuable to contradict the common assumption (and the attached feelings of shame, blame and stigma) that suicide primarily occurs in especially vulnerable families. Our study shows that suicide can occur in any family

9 FUTURE PERSPECTIVES

As the first publications resulting from our research, the papers in this thesis are wide-ranging and do not cover specific outcomes in detail. We will continue to investigate each of the outcomes more thoroughly, for example depression, anxiety and hazardous alcohol that need to be analysed in regard to sex and gender as well as time since loss. We will also use mixed-methods to explore our findings further. Another area that needs attention (also stressed by the suicide bereaved parents) is the need for support to **suicide-bereaved siblings.** PhD-student Rossana Pettersén, who is a clinical psychologist, is currently working on this project.

We found that several of the parents had tormenting feelings of guilt. There were also numerous parents that described how they are continuously battling with questions regarding why the suicide happened and what they could have done to prevent it from happening. We believe that these parents may benefit from **professional interventions** including information about underlying causes to suicide and practice in how to handle for example rumination.

The findings based on the surviving parents' perspective were included in the documents used to create regional and **national guidelines** for care of the suicidal patient[109,110]. We believe that national guidelines may also be useful in the care of suicide-bereaved individuals. The high prevalence of depression and guilt-feelings (found in our studies and those of others) suggest that some, although not all, parents may benefit from professional interventions. Our findings also show that offers of information and support need to be initiated by professionals.

New times bring new possibilities but also challenges. Electronic communication (web-sites, social networks, micro blogs...) provide sources of information and support but may also provide the opposite. Several parents told us that their son or daughter had been visiting websites or communities that promoted suicide, thus making clear to us the importance of providing counter forces like "Självmordsupplysningen.se"[111] and "Suiciderescue.se"[112] **The social media** may also be considered when other interventions are discussed for example regarding considerations concerning death notices. Being part of a large community of bereaved people may provide much needed instant and/or long-term support. On the other hand, continuous alerts about new and never ending traumas (similar to one's own) may cause additional distress and perhaps delay the healing process.

The need for **improved care of the suicidal patient** was strongly emphasised during the in-depth interviews and the data collection. The perceived lack of information as well as insufficient attempts to create an alliance between the patient, the caregivers and the family were also evident in the survey results, especially in the parents' written reports. We have started to use some of our findings in the education of healthcare personnel and students and will now continue to analyse the questions and written material with a focus on healthcare-related factors (before and after the loss) that might be amendable to change.

10 SVENSKT ABSTRAKT

Bakgrund Föräldrar som har mist en son eller dotter genom suicid riskerar att utveckla psykisk ohälsa som kan bli långvarig och till och med livshotande. Trots denna risk är forskningen kring suiciddrabbade föräldrar sparsam. En förklaring till att det saknas studier inom detta område är att forskning som inkluderar traumatiserade personer ofta hindras av rädslan för att personerna ska ta skada av kontakten. Ett annat skäl är metodologiska svårigheter. Målet med vår forskning är att förbättra den professionella vården av föräldrar som har förlorat en son eller dotter genom suicid. Den här avhandlingen beskriver de första stegen mot detta mål.

Metod Vi skapade hypoteser, frågeformulär och ett etiskt protokoll för kontakt och forskningsdeltagande i en förstudie som inkluderade 46 suiciddrabbade föräldrar (**artikel I**). Därefter använde vi en populationsbaserad enkät för att samla in data från föräldrar som hade förlorat ett barn (ålder 15 till 30 år) genom suicid, två till fem år tidigare. Sammantaget deltog 666 av 915 (73%) förlustdrabbade föräldrar och 508 av 666 (74%) icke-förlustdrabbade (matchade 2:1) i studien.

Resultat Vi fann att 633 (95%) av de förlustdrabbade föräldrarna upplevde att studien var värdefull och att 604 (91%) skulle rekommendera en annan förälder att delta. Bland de förlustdrabbade rapporterade 334 (50%) att de hade blivit positivt påverkade av sitt deltagande och 70 (11%) att de hade blivit tillfälligt negativt påverkade (de flesta hänvisade till att de kände sig ledsna). Flera bland de förlustdrabbade föräldrarna uttryckte ett behov av att dela sina erfarenheter om barnets suicid med andra och 639 (96%) ansåg att sjukvården ska kontakta föräldrar som har förlorat ett barn i suicid för att erbjuda hjälp och stöd (**artikel II**) Bland de förlustdrabbade föräldrarna tog 167 (25%) antidepressiv medicin och/eller var måttligt till svårt deprimerade enligt PHQ-9 (9% av de icke-förlustdrabbade, RR 2.7). Fjorton procent av de förlustdrabbade rapporterade att de hade haft psykologisk ohälsa för mer än 10 år sedan (14% bland de icke-förlustdrabbade, RR 1.0). Den högsta risken för psykisk ohälsa återfanns i gruppen av föräldrar med tidigare psykisk ohälsa **(artikel III)**. Bland de förlustdrabbade föräldrarna hade 460 (69%) sett sitt barns kropp under en formell visning, bland dessa föräldrar svarade 430 av 446 (96%) "nej" på frågan "Ångrar du att du såg ditt barn efter dödsfallet". Bland föräldrarna som inte hade sett sitt barn efter dödsfallet svarade 99 av 159 (62%) "nej" på frågan "Önskar du att du hade sett ditt barn efter dödsfallet" (**artikel IV**).

Konklusion Vi fann att majoriteten av föräldrarna upplevde sitt forskningsdeltagande som någonting positivt och att de flesta välkomnade kontakten med oss. Förlusten av ett barn var förknippat med hög förekomst av psykisk ohälsa två till fem år efter förlusten. Vi fann ingen skillnad i förekomst av tidigare psykisk ohälsa vid jämförelse mellan de båda grupperna av föräldrar. Den högsta förekomsten av psykisk ohälsa återfanns dock i gruppen bland förlustdrabbade föräldrar med tidigare psykisk ohälsa. Två till fem år efter förlusten, svarade nästan alla som hade sett sitt barn under en formell visning att de inte ångrade att de hade gjort det. Mer än hälften av de som inte hade sett, önskade inte heller att de hade gjort det.

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"Everything can happen, both sad and wonderful things"
Ludmilla Rosengren

"There is a land of the living and a land of the dead and
the bridge is love, the only survival, the only meaning"
Thornton Wilder

To all the mothers and fathers that I met during the years working with this study:
I will be forever grateful for the life changing insights that you have given me. You have showed me what an incredible strength a person may possess; and in the same time how fragile a human life might be. I will not forget to count my blessings (thus notice and appreciate them), every day for the rest of my life.

Thank you!

Preparatory Studies to a Population-Based Survey of Suicide-Bereaved Parents in Sweden

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Abstract. *Background:* There is a need for evidence-based guidelines on how professionals should act following a suicide. In an effort to provide empiric knowledge, we designed a nationwide population-based study including suicide-bereaved parents. *Aim:* To describe the process from creating hypotheses through interviews to the development of a population-based questionnaire. *Method:* We used interviews, qualitative analysis and various means of validation to create a study-specific questionnaire to be used in a nonselected nationwide population of suicide-bereaved parents and a control population of nonbereaved (N = 2:1). The Swedish Register of Causes of Death and the Multigeneration Register were used to identify eligible individuals. All presumptive participants received a letter of invitation followed by a personal contact. *Results:* We developed a questionnaire covering the participants' perception of participation, their daily living, psychological morbidity, professional actions, and other experiences in immediate connection to the time before and after the suicide. Almost three out of four parents (bereaved = 666, nonbereaved = 377) responded to the questionnaire. *Conclusions:* By involving parents early in the research process we were able to create a questionnaire that generated a high participation rate in a nationwide population-based study that might help us to answer our hypotheses about bereavement after suicide.

Keywords: suicide, bereavement, questionnaires, data collection, research design

Introduction

Suicide-bereaved parents are at risk of developing mental disorders such as depression, anxiety syndromes, and even future suicides (Kessing, Agerbo, & Mortensen, 2003; Li, Laursen, Precht, Olsen, & Mortensen, 2005; Li, Precht, Mortensen, & Olsen, 2003). Actions from professionals within the healthcare system, police, clergy, and funeral homes might reduce this risk (Clark, 2001; Jordan & McMenamy, 2004). Qualitative findings show that a respectful and caring attitude in professional encounters after a traumatic death is important, as is the manner in which the professional actions are carried out such as how the body is viewed and the death notification communicated (Grad, Clark, Dyregrov, & Andriessen, 2004). Chapple and Ziebland (2010) performed interviews with 80 individuals bereaved by suicide or other traumatic deaths. Their conclusion was that relatives should have the opportunity to view the body, even after a traumatic death. They also found that those who regretted seeing the body lacked a choice or preparation for doing so. They suggest that professionals should help bereaved persons by telling them what to expect and not to force a decision. They also highlight the need for more studies that could be used to guide professionals working with bereaved relatives after a sudden traumatic death.

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Existing register and qualitative surveys provide valuable information about bereavement, but they need to be complemented by studies that investigate associations between care-related factors and long-term outcomes. Due to ethical and methodological issues, observational studies of bereaved populations are often preferred over experimental studies. A high participation rate is essential for this kind of study, but given the nature of bereavement it can be a challenge to receive adequate participation rate (Forte, Hill, Pazder, & Feudtner, 2004; Stroebe, Stroebe, & Schut, 2003). The combination of a sensitive research population and sensitive questions is known to reduce the rate, while several means to increase the participation rate such as monetary incentives, systematically sending questionnaires, and mentioning a duty to respond (Burnell & O'Keefe, 2004; Edwards et al., 2009; Evans et al., 2002) are known but not applicable for ethical reasons. Another challenge is to identify an unselected group of bereaved individuals (Stroebe et al., 2003). National population-based registers in Sweden enable the identification of large unselected groups of bereaved parents, allowing data collection by study-specific questionnaires and testing of hypotheses. Despite this potential, population-based registers have rarely been used in bereavement research that includes contact with informants. One explanation is the conception that contact might cause retraumatization, and researchers have therefore been denied access to bereaved persons through population registers (Burnell & O'Keefe, 2004; Kreicbergs, Valdimarsdóttir, Steineck, & Henter, 2004). However, in recent years several population-based studies on bereavement were carried out in Sweden including parents who had delivered a stillborn baby and family members who had lost a spouse, a child, a sibling, or a parent to cancer (Hauksdóttir, Steineck, Fürst, & Valdimarsdóttir, 2010; Kreicbergs, Valdimarsdóttir, Onelöv, Henter, & Steineck, 2004; Rådestad et al., 2009; Valdimarsdóttir, Helgason, Fürst, Adolfsson, & Steineck, 2003). Utilizing the methods (Steineck, Hunt, & Adolfsson, 2006) and experiences from these data collections, we designed a study of suicide-bereaved parents. We aim to describe the successive stages in a preparatory study designed to develop a study-specific questionnaire and means for retrieving the information. We also present the participation rate and the mean response rate to our questions from the nationwide main data collection.

Method

Qualitative Prestudy

We aimed to create a questionnaire customized for the study-specific research questions and hypotheses in the main study. With the approval of the Regional Ethics Committee at the Karolinska Institute for the whole study, we started by collecting data through interviewing parents who had lost a son or daughter to suicide and sorted the data qualitatively.

Study Population

We decided on the inclusion criterion loss of a child age 15–30 years to suicide during the preceding 2–5 years and contacted bereaved parents by means of purposive sampling. Seventeen parents chose to participate. We identified them in records from a psychiatric department in Stockholm (*N* = 4), an advertisement in a local newspaper (*N* = 1), and contact with a nationwide self-help group for Swedish suicide survivors ("SuicidPrevention och efterlevande stöd – SPES") (*N* = 12). The self-help group is religiously and politically independent. The mothers (*N* = 11) and fathers (*N* = 6) were between 51 and 78 years old; 12 had lost sons and five daughters. One son had been adopted and one parental couple had lost two sons to suicide. Three mothers were divorced and lived alone, while the rest of the participants lived together with the other parent of the deceased child. Six couples from this set of parents were interviewed, mothers and fathers separately, and for two other couples only the mothers were interviewed. Fifteen of the parents had lost their child 2 to 5 years before the interview and two parents, married to each other, had lost their child 26 years prior to the interview. All of the offspring's were between 16 and 30 years old when they suicided, and five of them had been living with their parents at the time of death. The medical histories of the deceased ranged from no previously identified psychological illness to long-term psychiatric morbidity with several suicide attempts preceding the suicide.

Interviews

We started all interviews with the question: "Can you tell me about your son or daughter?" Most parents told their story as a narrative: They began by describing the child and the events that built up to a change, the first suicide attempt or the suicide, and the time after the suicide when the parent tried to make sense of life again. All but three narratives covered the areas of our working hypotheses and complementary questions were seldom needed. Four interviews took place at the hospital and 13 in the parent's home. The interviewer was usually invited by the parents to spend the whole day with them in order to be able to learn about the family and the deceased child by reading letters, seeing pictures, and visiting important places. All interviews were recorded and included in our qualitative sorting.

Qualitative Sorting

The interviews were sorted qualitatively (Graneheim & Lundman, 2004) through:

1. Verbatim transcribing the recorded interviews.
2. Dividing the transcripts into quotations, i.e., sections of text with similar content and context and each section labeled with a code.

3. Shortening of long quotations while preserving the core and sorting of the quotations into a separate document according to their codes.
4. Grouping of all codes and quotes into subcategories and categories.
5. Interpreting the qualitative information (first and last author) and repeating the steps above until no new codes could be identified despite further interviewing (saturation).
6. Considering the entire context by repeatedly comparing the interviews with previous research findings while working with the questionnaire draft and the working hypotheses.

We used the software Open-code (Umeå University, Sweden) to divide the transcripts into quotes with codes (Figure 1). In parallel, we started to construct the questionnaire draft by dividing the information into three categories: the death, the time before the death and the time after the death. "The time before death" included the time from the child's birth until he or she suicided, "the death" the time from finding out about the death until the funeral, and "the time after death" the time from the funeral until the day for the interview (Figure 1). This division was done according to how the majority of narratives were told during the interviews. We continuously sorted the codes and their quotes into the questionnaire draft, first according to the three categories, then in subcategories that we gradually rewrote into questions. After saturation had been reached, the questionnaire consisted of 306 questions. "The time before death" was the category most strongly emphasized by the parents, since they were eager to describe their child as a person and their disappointment with school or healthcare. "The death" generated fewer quotations, most of which were about encounters with professionals such as the police or the ambulance crew saying or doing something that the parents perceived as positive or negative. Despite the brevity of the parents' accounts of this phase, we created many questions for this section since detailed information about the parent's views on, for example, the death notice and circumstances surrounding seeing the dead child will be important if it turns out that professional interactions with the parents need to be improved. "The time after death" generated the least number of quotations. Information about a perceived lack of professional support and about the importance of support groups for suicide survivors dominated in this category.

Creating the Questions and the Questionnaire

We used the parents' own wording when we created the questions. Each question was formulated to measure one conceptual entity and was to be answered by choosing one response alternative (Alderman & Salem, 2010; Charlton, 2000), mainly measuring intensity and incidence (Figure 2). All response alternatives had been tested in previous studies within our research group (Onelöv et al., 2007; Skoogh et al., 2010; Steineck et al., 2006). We put questions on present well-being at the beginning of the questionnaire, since questions that raise emotions might affect the answers concerning present health (Hauksdóttir, Steineck, Fürst, & Valdimarsdóttir, 2006). We used psychometric scales for measuring three of the outcomes: the 9-item depression scale of the Patient Health Questionnaire (PHQ9; Kroenke, Spitzer, & Williams, 2001), the 2-item Generalized Anxiety Disorder scale (GAD2; Kroenke, Spitzer, Williams, Monahan, & Lowe, 2007), and the Alcohol Use Disorders Identification Test (AUDIT; Allen, Litten, Fertig, & Babor, 1997). Considering the results from the validation process, and to conform with the answering categories in the rest of the questionnaire, we slightly modified the PHQ9 and GAD2 sets of answering alternatives from *Not at all, Several days, More than half the days, Nearly every day* to *Not at all, 1–3 days a week, 4–5 days a week,* and *6-7 days a week*, using the same system for scoring. To further clarify the content, we divided two questions from PHQ9 into four: (1) "Feeling bad about yourself or that you are a failure," (2) "Feeling that you have let yourself or your family down," (3) "Moving or speaking so slowly that other people could have noticed," and (4) "Being so fidgety or restless that you have been moving around more than usual." In addition to the psychometric scales and our adhoc questions based on the interviews, we created single-item questions to capture symptoms related to depression and anxiety disorders as defined in the *Diagnostic and Statistical Manual Fourth Edition (DSM-IV)* (American Psychiatric Association, 1994) when defining the entities of outcomes related to psychiatric morbidity (Figure 1). We modified questions regarding research participation from similar questions in previous research (Dyregrov, 2004; Kreicbergs, Valdimarsdóttir, Steineck et al., 2004).

Validation of the Questionnaire

A total of 46 suicide-bereaved parents were involved in the validation process; 17 had already been interviewed and 29 were new to the study. The parents who were new to the study matched our inclusion criterion for the main study described below and we recruited them through the membership register of the support group for Swedish suicide survivors (SPES). We used four different means of validation:

1. The parent answers the questionnaire draft face to face with the researcher: The first parents ($N = 3$) who were involved in the validation process answered the questionnaire in the presence of the interviewer while thinking aloud. Since we soon discovered that the parents' comments ceased as their energy declined, this means of validation was replaced by the ones below.
2. The parent answers the questionnaire draft alone while writing comments: The parents ($N = 43$) answered the questionnaire by themselves. While answering, they

Quotes	Codes and subcategories	Questions

Examples from the category “After the death”
Quotes from an interview with a father who lost a 26-year-old son 3 years ago:
“When I went back, out from the house, I bumped into him; he was hanging in the apple tree. I took him down and shouted for my wife…”
“… and she called the ambulance, they couldn’t find their way so she had to drive and meet them, it was hard. The policemen came and said that it’s always sad when things like this happen. They kind of lacked empathy, I guess education as well…”
”I don’t have nightmares, but it comes up in my thoughts. It is so etched in the brain; I can see exactly how it looked and what happened next. It will always be like that. On the whole, not one day passes without me thinking about it.”
Quotes from an interview with a mother who lost her 22-year-old son 5 years ago:
“The female police came forward and told my husband, `You were right, he was in the apartment,´ and we just said, `How did he do it?´ He had hung himself…”
“We were standing outside and the female police was laughing at something … I just wanted to ask, what do you laugh about, THERE IS NOTHING TO LAUGH ABOUT...”
“… The police asked if we wanted to see him but we didn’t. And he thought that this was good. He was blue on his hands and so on. But then I felt, just a week after…that I wanted to see him.”
“… and they had made him so nice. They had put on some clothes. And they had covered the hands, because he was still blue and he had marks on his neck. Still it felt very good to have seen him.”
	Examples from the category “After the death”
	The suicide
	How the son or daughter died
	Finding the child
	If the parent found the child or received a death notice
	The death notice
	If the parent received a death notice from a professional person
	How and when the parent received the death notice
	Seeing the child
	If and where the parent saw the child after the death and if it was under appropriate circumstances
	Professional encounters
	What professionals the parent met in connection to the death
	If any of the professionals said or did something that affected the parent positively or negatively
		Examples from the category “After the death”
		How did you find out about your child’s death?
		☐ It was me who found my child
		☐ I saw my child just after …
		☐ Through a private talk
		☐ A person-to-person phone call
		☐ By writing
		☐ In another way, namely:_____
		When we write “see your child,” we also mean if you only saw the outline of your child or, for example, his or her hand.
		Did you see your child at the funeral home?
		☐ No
		☐ Yes → If yes, was it under appropriate circumstances?
		    ☐ No
		    ☐ Yes, a little
		    ☐ Yes, moderate
		    ☐ Yes, much
		Did you have contact with the police in connection to your child’s death?
		☐ No
		☐ Yes → If yes, were you satisfied with the contact?
		    ☐ No
		    ☐ Yes, a little
		    ☐ Yes, moderate
		    ☐ Yes, much

	Examples from the category well-being and ill-health (outcomes) ***Thoughts about the suicide*** If the parent thinks about the child’s suicide ***Nightmares*** If the parent suffers from nightmares about the child’s suicide ***Intrusive thoughts*** If the parent suffers from intrusive thoughts about the child´s suicide	**Examples from the category well-being and ill-health (outcomes)** Answer how it has been during the last month even if it’s not a typical month for you. Have you relived your child’s death through nightmares during the last month? ☐ No ☐ Yes, occasionally ☐ Yes, 1-3 days a week ☐ Yes, 4-5 days a week ☐ Yes, 6-7 days a week

Figure 1. Construction of questions

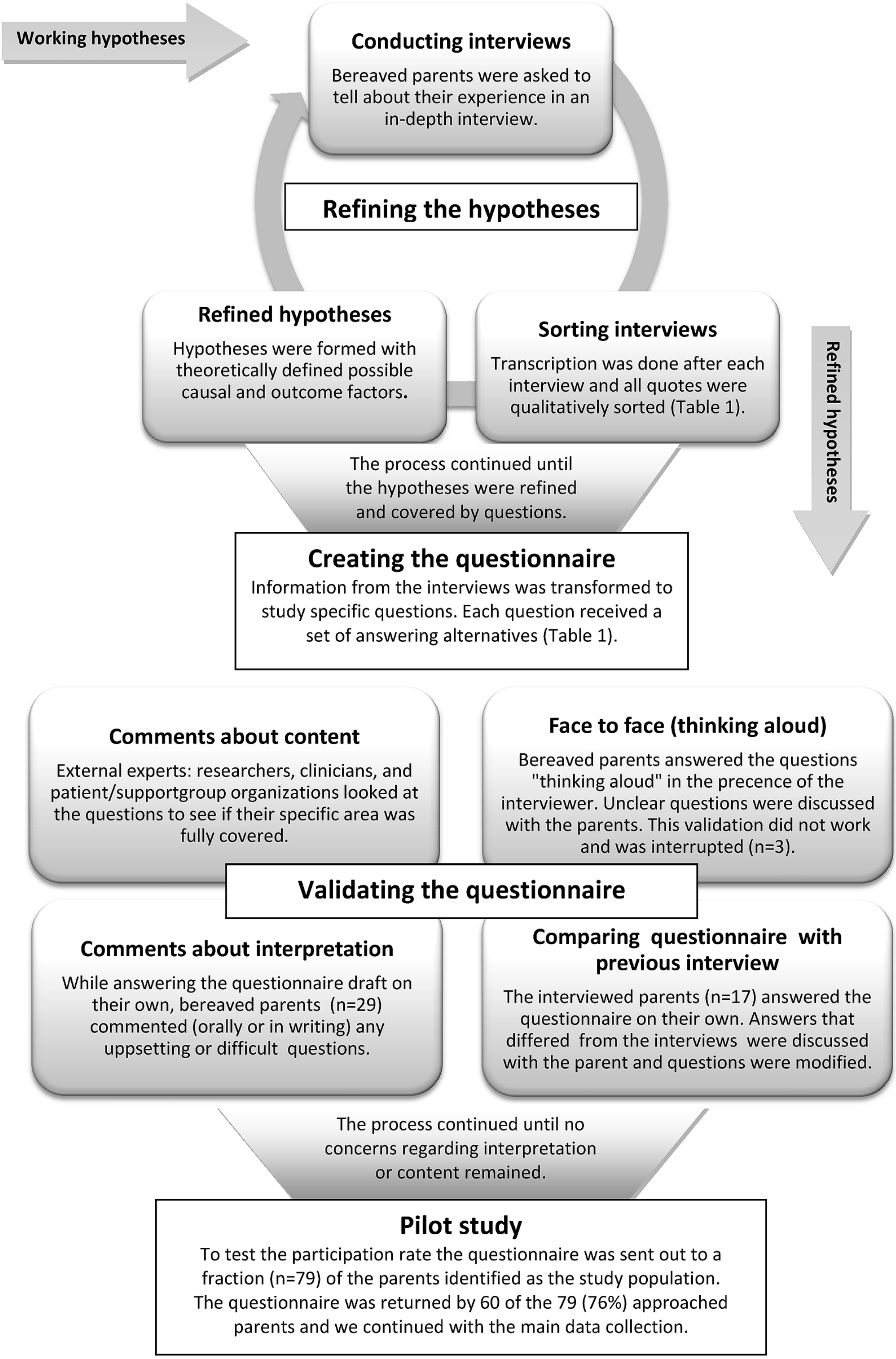

Figure 2. Developing the questionnaire.

Table 1. The questionnaire for the bereaved parents

Sections (no. of questions[1]) Example of content	Response rate % Mean (range) Main study $N = 666$	Main timeframe of questions	Main origin of questions	Function in analyses
Background (12)				
Sex and age of parent. Birth and death of the deceased child.	100 (99–100)	Present Actual date	Previous research	Effect modifier Confounder
Well-being and ill-health (40)				
Prevalence of depressive and anxiety symptoms.	99 (98–100)	Last 2 weeks Last month	Previous research Clinical experiences	Outcome
Before death (18)				
Experience of the child's distress/health care before the suicide.	99 (96–100)	The month before death	Clinical experiences In-depth interviews	Effect modifier Confounder
The death (48)				
Death notice, received information, viewing the body.	96 (80–99)	The death day The month after death	Clinical experiences In-depth interviews	Exposure
After the death (35)				
Grief, coping and professional/peer support.	96 (87–99)	Present The year after death	Previous research Clinical experiences	In-depth interviews
Suicidality (4)				
Prevalence of suicide attempts before and after the death.	99 (98–99)	> 10 years ago ≤ 10 years ago	Previous research Clinical experiences	Effect modifier Outcome
Previous losses (5)				
Death within the family and/or other important losses.	99 (98–100)	During upbringing Actual year	Previous research Clinical experiences In-depth interviews	Effect modifier Confounder
Daily living (27)				
Work and sick-leave, spare time and alcohol consumption.	97 (88–99)	Present Last 2 weeks	Clinical experiences In-depth interviews	Effect modifier Confounder Outcome
Participation (7)				
Negative and positive effects of participation.	97 (94–99)	Present	Previous research Clinical experiences In-depth interviews	Outcome
Total main questions (196)	98 (80–100)			

Note. [1]Questions ($N = 196$) created to be answered by all suicide-bereaved parents ($N = 666$).

noted in writing if they found a question difficult, confusing, upsetting, insulting, or negative in any other way. Their written comments as well as multiple, missing or confusing answers were discussed by telephone with the interviewer.

3. Comparing information from the interview with the questionnaire: The interviewer compared the information from the answered questionnaires with the interviews ($N = 17$) and discussed any incongruities with each parent.
4. Comments about content: To ensure that important issues for our research questions and hypotheses were covered, we asked external experts such as suicide researchers and clinicians to review the questionnaire. We also asked the parents who were involved in the validation process whether they thought that all important issues regarding their loss had been covered.

Modifying the Questions and the Questionnaire

The validation revealed that some questions needed modification, for example: "How did your child take his or her life?" One mother stated during the interview that her daughter died by taking an overdose of antidepressant drugs, while she did not answer this question in the questionnaire. She did not want her daughter's death to be associated with illegal drugs and therefore avoided the alternative "Poisoning with, e.g., drugs or medication." Accordingly, we changed it to "Poisoning with, e.g., medication, chemicals or some kind of gas." The alternative "Some kind of gas" was merged with "Poisoning" after another comment about "some kind of gas" and "poisoning" being synonymous. There were divergent opinions among parents about whether to use the term self-murder or suicide. "Self-murder" is used in Sweden, but it is not considered as neutral as suicide and can be associated with criminality. The term suicide, on the other hand, can be perceived as an attempt to distance oneself from the subject. After discussing with external experts, we decided to use the wording "to take his or her own life" when possible and otherwise "self-murder," since these terms are more commonly used among nonprofessionals in Sweden. To further clarify the meaning of some questions we added information boxes (Figure 1). In accordance with step four in the validation process, we added questions that the parents found important such as: "Are you ashamed over your son's or daughter's suicide?" Several parents thought that we ought to add more questions about the siblings. We met this request by including these questions in an ongoing study about the loss of a sibling to suicide. Some questions were considered difficult to answer, for example, those about the parents' view on participating in the study. We solved this by adding space for free comments. Several participants told us that the questionnaire was too voluminous, and that many questions were similar and some irrelevant. We therefore rewrote and reduced the 306 questions to 196 with follow-up questions and fields for free comments (Table 1). We also created a shortened version of the questionnaire for our control group of nonbereaved parents with 93 questions, follow-up questions and fields for free comments. In this questionnaire we included the questions that concern the parents' well-being and daily life, as well as the psychometric scales mentioned above.

Data Collections

Study Population

We identified all individuals 15 to 30 years old (*N* = 747) who had suicided between the years 2004–2007 by using the Swedish National Register of Causes of Death and their parents through the Multigeneration Register (*N* = 918). A comparison group of nonbereaved parents (*N* = 508) was identified from the Swedish Population Register. For the parents, we decided on the following inclusion criteria: alive, born in a Nordic country, able to communicate in Swedish, loss of only one child, and with a listed address and telephone number. The parents in the comparison group had an offspring born the same year as the deceased son or daughter from the study group and were matched for age, sex, living area, and number of children. In total we received names and addresses of 1,426 parents; we did not know at this stage whether they belonged to the group of bereaved or nonbereaved parents. We sent an introductory letter to all eligible parents including information about the study and a statement that participation would be voluntary and could be interrupted without explanation at any time. We also informed them that the questionnaire could be returned anonymously if they wanted to. After one week, the first author or an experienced research assistant telephoned each parent to inquire whether he or she wanted to see the questionnaire corresponding to them. We asked those who agreed to see a questionnaire to reveal whether they belonged to the group of bereaved or nonbereaved and also asked for permission to call again if the questionnaire was not returned within one month. We formatted the questionnaire as a booklet and parents that returned questionnaires in which a complete spread was empty were contacted again to investigate whether they had left those pages by mistake. We tested the logistics, participation rate, internal response rate and the parents' experience of participation through a pilot study.

Results

In the pilot study, we sent the introductory letter to 79 randomly selected parents of the 1,426 identified as the study population and contacted them by telephone. Sixty-five (82%) agreed to see the questionnaire, while 14 (18%) declined participation – seven without leaving an explanation, one on behalf of his wife, three because they never participate in research studies, two because they disagreed regarding suicide being the cause of death, and one because of a physical illness. Within 1 month, 46 (58%) of the parents approached had returned the questionnaire, 28 bereaved and 18 nonbereaved. Of these 46, 45 stated that they found the survey valuable, 24 that they were positively affected, and 3 that they were negatively affected by their participation. Most of the bereaved parents' comments about their research participation were about being grateful for the opportunity to tell about their experiences. The nonbereaved parents commented on appreciating the reflections raised by their participation and also about being more grateful for things they used to take for granted such as their psychological health and being a parent. In the questionnaire answered by bereaved parents the mean internal response rate was 98% (range 82–100%) for the main questions. Based on these results we decided to continue with the main study.

We sent the letters 50 at a time for ethical reasons, meaning that we wanted to be able to provide support to the participants throughout the study and to be able to stop the data collection if we found any indication that participation was harming the parents. The main study was recently completed, and we are in the process of analyzing the extensive data collection. The results will be presented in upcoming publications. In total, 1,043 (73%) of 1,426 parents participated in the study, 666 (73%) of 918 were bereaved and 377 (74%) of 508 nonbereaved. The mean internal response rate on the questions created to be answered by all parents was 98% (80–100%) for the bereaved (Table 1) and 99% (82–100%) for the nonbereaved. Nine questions had a mean response rate of 90% or less: four regarding the death notification, four concerning support groups, and one from the psychometric scale AUDIT. A whole spread of questions was missing in 77 of the 666 (12%) questionnaires from the bereaved parents. Of these, 21 had chosen to be anonymous and could not be contacted again, and six had deliberately left the questions unanswered. We contacted the remaining 50 informants and asked them to fill in the missing questions, and 38 (76%) did so.

Hypotheses and Outcomes

Our main outcomes were quality of life, physical health, psychological health including guilt feelings, regrets, depressive symptoms, anxiety and signs of posttraumatic stress, and alcohol consumption 2 to 4 years after the death. We compared bereaved and nonbereaved parents regarding all of the outcomes except those connected to the child's death such as regrets. The research hypotheses (Table 2) that will be tested within the group of bereaved include (1) the time before death, (2) the death, and (3) the time after death with variables covering:

1. Parent's relationship to the child, experience of the child's healthcare, conversations with the child about death and/or suicide, worries about the child's mental health and about the child taking his or her life (emotional preparedness), experience of the child's suicidal communication (emotional preparedness), and consideration that the child might have taken his or her life before finding the dead child (emotional preparedness) during the year prior to the suicide.
2. Timespan between death and death notification, death notification delivered face to face, information about cause of death at the time of death notification, parent discovering the body of the dead child, viewing the body of the deceased child during dignified circumstances, and receiving professional care in connection with viewing the body.
3. Parent receiving information about possible medical causes of suicide, having general knowledge about causes of suicide, not having someone to share their emotional burden with, receiving individual grief support, participating in support groups or other groups for bereaved persons, and the dead child not being an only child.

Table 2. Examples of hypotheses

Suicide-bereaved and nonbereaved parents

1. Bereaved parents have higher prevalence of self-rated anxiety, depression and harmful alcohol consumption in comparison with nonbereaved parents.
2. Bereaved parents have higher prevalence of sick-leave in comparison with nonbereaved parents.
3. The loss, rather than previous psychological morbidity, explains excess psychological morbidity among bereaved parents in comparison with nonbereaved parents.

Suicide-bereaved parents

Hypotheses related to the time before death

4. Parents who have talked with their child about death prior to the suicide do not regret the talk.
5. Parents that worried about the child committing suicide prior to the suicide (emotional preparedness) have lower prevalence of psychological distress in comparison with parents who did not worry.

Hypotheses related to the time between the death and the funeral

6. Parents who viewed the body during worthy circumstances do not regret doing so.
7. Parents who viewed the body during unworthy circumstances have higher prevalence of intrusive thoughts and nightmares.
8. Parents that received the death notification close to the time of death have lower prevalence of psychological distress in comparison with those who experienced a long time span between death and death notification.

Hypotheses related to the time after death

9. Parents that lack someone to share their innermost feelings with have higher prevalence of psychological distress than parents who do not.
10. Parents that believe that the child's suicide was caused by psychiatric illness have lower prevalence of self-rated shame and feelings of guilt in comparison with parents that believe the opposite.
11. Parents' excess levels of psychological morbidity are reduced by time since the loss.

Discussion

Our preparatory studies resulted in a questionnaire that was answered by 1,043 (73%) of the 1,426 eligible parents, and the mean response rate of the questions was 98% for the bereaved parents and 99% for the nonbereaved. We used several means to ensure a high internal response rate. We involved parents that had lost a child to suicide in the creation of the questionnaire (Charlton, 2000) through interviewing and qualitatively sorting the interview material. In doing so we were able to formulate questions that were judged to be relevant to the study population. We took particular interest to ensure that the questions could be understood correctly and that they would not be experienced as insensitive or intrusive in any way (Alderman & Salem, 2010; Charlton, 2000). During the validation process, we encouraged the parents to provide us with comments on how they had experienced the questions, and we made appropriate modifications to take their comments into account. We also tested that each question contained only one concept as well as satisfactory response alternatives for each question.

We carried out a literature search and used external experts to ensure that the questionnaire covered the aspects of the experience that both the bereaved parents and the healthcare professionals saw as important. Another area for attention was the layout of the questionnaire. By adding information boxes and space for additional comments, we provided the opportunity to express important issues using free writing (Alderman & Salem, 2010; Charlton, 2000). Despite this, the response rate below

90% for eight of nine questions could be explained by the layout since 82–99% of the persons who left these questions unanswered had answered a preceding main question with a "no" and left the complementing questions unanswered instead of answering them with the alternative "not applicable." The ninth question with a low response rate was part of the Alcohol Use Disorders Identification Test (AUDIT) and could be explained by lack of an applicable response alternative.

A large number of questions in a questionnaire and the presence of sensitive questions generally may reduce participation rate (Edwards et al., 2009). Despite this risk we chose to give priority to the breadth of the questionnaire for the bereaved parents and included a substantial number of questions, many of which had a sensitive content. Burnell and O'Keefe (2004) stress the importance of not persuading sensitive research persons to answer particular questions. Therefore, we did not contact parents who had left out answers to one or several questions, even though this might have had a positive effect on the internal response rate. However, for the 77 questionnaires where a whole spread of questions were missing we considered the possibility that these pages had been left out by mistake since we could not discern any patterns regarding content of the questions. They had a high response rate among other participants (Table 1) and were about professional contacts after the death of the child, recreational activities, and the perception of participating in the study. Our suspicion was confirmed when we sent a letter asking for complementing answers to the informants that had chosen not to be anonymous and a majority (76%) returned the complementary addition.

We tested the internal response rate as well as the bereaved parents' experiences in the pilot study (Alderman & Salem, 2010; Charlton, 2000; Kreicbergs, Valdimarsdóttir, Steineck et al., 2004). Since the response rate was sufficiently high, we made no changes before starting the main study. The pilot study also showed us that the bereaved parents experienced both their contacts with the researchers and participation in the study as positive. Thus there were no discernible ethical obstacles to perform the main study.

We took several measures to maintain a high participation rate (Edwards et al., 2009) and reached 73%, which is considered by Alderman and Salem (Alderman & Salem, 2010; Charlton, 2000) as sufficiently high to avoid systematic errors related to dropout. In upcoming analyses, we will evaluate any possible effects of dropout on the results with respect to each hypothesis. The prospective informants were contacted according to a carefully tested scheme that included contact via handwritten letters, telephone, and repeated reminders (Edwards et al., 2009). The pilot study indicated that the scheme worked. Personal contact is expensive and time consuming, but previous studies have shown that access to personal information and provision of support during participation is meaningful in studies that include vulnerable individuals (Dyregrov, 2004). Two persons with substantial experience in talking with bereaved individuals handled all of the personal contacts, and the contact also provided us with the opportunity to refer parents with psychiatric health problems such as depression to professional providers when needed. A disadvantage with a personal contact is that it might affect how participants answer the questions. However, considering the size of this study and that only a few parents needed extra support or information during participation, we believe this effect to be minor if any.

As a matter of good ethical practice, we immediately accepted a "No" to participate without asking about the reason, even though a continued conversation might have led to an agreement and thereby to a higher participation rate (Burnell & O'Keefe, 2004; Evans et al., 2002). Likewise, parents who declined or interrupted their participation after an initial acceptance were not contacted again. Those who did not wish to participate were able to avoid personal contact by declining participation via e-mail, letter, text message, or telephone voice mail. They could also choose to answer the information letter anonymously, which according to previous studies raises the frequency of replies (Edwards et al., 2009). Only one fifth of our population chose this alternative.

It has been argued that validated measures should be used over self-administrated questions. However, since most concepts in this study had not previously been validated we had to design and validate ad hoc questions (Table 1). Alderman and Salem (2010) consider this as possible providing rigorous validation, and we therefore employed a comprehensive validation process in order to create questions that measured what we wanted to measure. Since each question contained only one conceptual entity, they provided information with less noise. By comparing information from the bereaved parents' questionnaire with information from their interviews we were able to correct any lack of clarity or misunderstanding (Charlton, 2000). We used study-specific questions as well as slightly modified versions of the psychometric scales PHQ9 and GAD2 to measure symptoms of anxiety and depression (Onelöv et al., 2007; Skoogh et al., 2010). The modification was done as a result of the validation process. We also found that the use of answering alternatives for incidence instead of prevalence influenced the response rate positively.

We identified possible confounding factors by using our qualitative preliminary study that included literature review, contact with external experts, interviews with bereaved parents, and qualitative sorting (Charlton, 2000). We constructed the questions in such a way as to make possible adjustments for confounding factors through stratification and other statistical methods and engaged a statistician early in the research process. This contributed to further evaluation of our adhoc questions and made it possible to reach a sufficiently high statistical power for analyzing our data in a suitable manner (Alderman & Salem, 2010).

Our results show that it is possible to create a detailed questionnaire regarding loss to suicide by involving bereaved parents early in the research process. We used the questionnaire in a nationwide population-based study with a high participation rate and will use the results to test our hypotheses about suicide bereavement. Knowledge about bereavement after suicide is needed to support future decisions of professional actions aimed at this group of bereaved.

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ORIGINAL ARTICLE

The ethics of doing nothing. Suicide-bereavement and research: ethical and methodological considerations

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Background. Valuable trauma-related research may be hindered when the risks of asking participants about traumatic events are not carefully weighed against the benefits of their participation in the research.

Method. The overall aim of our population-based survey was to improve the professional care of suicide-bereaved parents by identifying aspects of care that would be amenable to change. The study population included 666 suicide-bereaved and 377 matched (2:1) non-bereaved parents. In this article we describe the parents' perceptions of their contacts with us as well as their participation in the survey. We also present our ethical-protocol for epidemiological surveys in the aftermath of a traumatic loss.

Results. We were able to contact 1410 of the 1423 eligible parents; eight of these parents expressed resentment towards the contact. Several participants and non-participants described their psychological suffering and received help because of the contact. A total of 666 suicide-bereaved and 377 non-bereaved parents returned the questionnaire. Just two out of the 1043 answered that they might, in the long term, be negatively affected by participation in the study; one was bereaved, the other was not. A significant minority of the parents reported being temporarily negatively affected at the end of their participation, most of them referring to feelings of sadness and painful memories. In parallel, positive experiences were widely expressed and most parents found the study valuable.

Conclusions. Our findings suggest, given that the study design is ethically sound, that suicide-bereaved parents should be included in research since the benefits clearly outweigh the risks.

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Key words: Bereavement, epidemiologic methods, ethics, research design, suicide.

Introduction

The trauma of losing a family member to suicide poses risk that survivors will experience complicated grief and long-term psychological morbidity (Kessing *et al.* 2003; Li *et al.* 2005; Groot *et al.* 2006). Adequate professional intervention might reduce this risk, but the development of evidence-based practice has been delayed by the lack of evidence-based knowledge. Institutional review boards sometimes hesitate to approve trauma-related research arguing that the contact might be hurtful and even re-traumatizing for some individuals. The risks of asking participants about traumatic events may, however, be overestimated and the benefits not considered. Therefore valuable research may be hindered (Kreicbergs *et al.* 2004*b*; Becker-Blease & Freyd, 2006; Jorm *et al.* 2007; Legerski & Bunnell, 2010).

Participants' experience of research participation has often been investigated by asking about their positive or negative emotional reactions immediately after their participation. Negative emotional reactions are often called 'distress' and may be described by using terms like: 'stress, anxiety, depression, embarrassment, discomfort, negative reaction, regret of participating and intrusion of privacy' (Jorm *et al.* 2007). Compilation of trauma-related studies suggests that a minority of participants become distressed when being interviewed or when filling out a questionnaire and that the distress quickly diminishes (Runeson & Beskow, 1991; Dyregrov *et al.* 2000; 2011; Dyregrov, 2004; Galea *et al.* 2005; Becker-Blease & Freyd, 2006; Jorm *et al.* 2007; Legerski & Bunnell, 2010).

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The long-term effects of participation in research have not been well studied, however (Jorm *et al.* 2007; Legerski & Bunnell, 2010). A few studies have investigated suicide-bereaved individuals' experience of research participation using a follow-up separated from the first survey or interview. Dyregrov (2004) performed a survey on psychosocial health and support among Norwegians (n=262) who had lost a child to suicide, sudden infant death syndrome (SIDS) or an accident between 1997 and 1998. The survey was followed up by in-depth interviews (n=69) in 1999 and a survey about the research experience, 2–4 weeks after. The survey showed that all parents (n=64), even the ones who expressed the most distress and pain, evaluated their participation as positive. Runeson & Beskow (1991) explored the reactions of suicide-bereaved relatives (n=58) to research participation using a structured telephone interview 2 weeks after a psychological autopsy interview and found that: 83% felt better than they had immediately after the autopsy, 57% felt better in comparison with how they had felt before the autopsy and none felt worse.

Recalling a traumatic event by telling, writing or answering questions might raise the level of short-term distress but is unlikely to cause re-traumatization or long-term harm. The temporary distress must, however, be acknowledged (Jorm *et al.* 2007; Legerski & Bunnell, 2010). Jorm *et al.* (2007) conclude that informants who might be vulnerable to distress should be treated with care but not excluded from research *per se*. Authors of several studies that included suicide-bereaved persons constructed ethical guidelines on how to reduce distress during research (Runeson & Beskow, 1991; Dyregrov, 2004; Jorm *et al.* 2007; Legerski & Bunnell, 2010). In planning our study, we considered these guidelines as well as experiences from previous studies. Despite these precautions, the regional institutional ethical committee disapproved our application with the explanation 'great risk that a number of research participants will end up in a crisis situation or feel psychologically un-well while answering the questionnaire'. After appealing to the central institutional ethical committee, we received approval and were able to apply for our study population of suicide-bereaved and non-bereaved parents from the national registries. However, despite our ethical approval the state authorities denied our request referring to the sensitive subject and the law of secrecy. We therefore developed a new ethical protocol for epidemiological surveys of suicide-bereaved persons. In this article we present our protocol and how our study population perceived both contact with us and participation in our survey.

Method

We developed our study design from a method that has been applied in several bereavement-related studies at the Division of Clinical Cancer Epidemiology (Kreicbergs *et al.* 2004*a*; Hauksdóttir *et al.* 2006; Rådestad *et al.* 2007; Omerov *et al.* 2013). The threats to validity were addressed by employing epidemiological methods as transferred to this field by the hierarchical step-model for study design, analysis and data interpretation (Steineck *et al.* 2006). The ethical considerations applied throughout the preparatory study and the epidemiological main study are summarized in our ethical protocol presented in Table 1.

Preparatory study

The overall aim of our study was to improve the professional care of suicide-bereaved parents by identifying aspects of care that could be amenable to change. We created our hypotheses and a questionnaire in our pre-study that included: a literature review, in-depth interviews with 17 suicide-bereaved parents, qualitative content analysis, validation of the questionnaire and a pilot study. The validation process involved 46 suicide-bereaved parents and external experts such as other researchers and clinicians (Omerov *et al.* 2013). Along with ensuring the validity of the questions we also strove to phrase the questions as inoffensively as possible. The questionnaire for the suicide-bereaved parents contained 196 main questions with follow-up questions and fields for free comments covering the time before death, the death and the time after the death. Our primary outcome of depression was measured by the nine-item depression scale of the Patient Health Questionnaire (PHQ-9) (Kroenke *et al.* 2001; Omerov *et al.* 2013). Symptoms of anxiety and depression were also assessed by study-specific questions based on the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) criteria (APA, 1995; Omerov *et al.* 2013). Since depression and anxiety are common in the general population we included a matched control group of non-bereaved parents for comparison. The non-bereaved parents received a shortened version of the questionnaire that had 93 questions, follow-up questions and fields for free comments. In this questionnaire we included the questions that address the parents' well-being and daily life, as well as the psychometric scales. The questions regarding research participation presented in Table 2 were developed from similar questions in previous research (Dyregrov, 2004; Kreicbergs *et al.* 2004*b*).

Epidemiological main study

The parents that had lost a 15- to 30-year-old son or daughter through suicide 2–5 years earlier were

Table 1. *Suicide-bereaved and non-bereaved parents – a Swedish population-based survey: summary of ethical protocol for epidemiological surveys on suicide-bereaved persons*

I. Preparation
- Carefully plan the inclusion criteria
- Same introductory letter to bereaved and non-bereaved
- To meet requirements of the Swedish law of secrecy, the researchers do not receive information about the person's bereavement status. This was revealed by the informants themselves, after they had consented to being sent a questionnaire
- Carefully consider when to send the introductory letter, e.g. avoiding death, name and birth dates
- Make time, be prepared for long conversations with presumptive informants
- Create a database for all communication and contact information

II. Introductory letter
- Contact information of researchers, e.g. toll-free telephone number, availability 24 h
- Focus of the study and the questionnaire
- Possible negative and positive experiences of participation
- Option to end participation at any time without explanation
- Opportunity to decline contact or participation
- Several ways to decline contact or participation, e.g. by telephone, email and text
- Inform about upcoming telephone call – when and by whom
- Consider and decide how many letters to send at a time in order to be able to consider and respond to informants' reactions and questions

III. Telephone call
- Carefully consider when to make the telephone call, e.g. avoiding death, name and birth dates
- Telephone call by trained interviewer
- Careful sensitive 'step-by-step' approach going from general questions to more detailed ones
- Being responsive and prepared for questions and need of support
- Provide support and help with referral if needed
- Encourage contact again if help or support is needed
- Give enough time for questions and support
- Accept a denial directly without further probing
- Repeat option to end participation at any time without explanation
- Ask for consent to send a questionnaire
- Ask for consent to call again within a time agreed upon

IV. During participation
- Continuity throughout the study with the same trained interviewers
- Interviewers being available and prepared for questions and support 24 h
- Provide support and help with referral if needed
- Give enough time for questions and support
- Give enough time for participation, e.g. being able to return questionnaire within a wide time-frame
- Ask for consent to call again during participation

identified by linkage of the Swedish Cause of Death Register and the Multi-generation Register. To be included in the study, the parent had to be born in one of the Nordic countries, be able to communicate in Swedish and have an identifiable address and telephone number. Furthermore, parents that had lost more than one child were excluded. A random sample of non-bereaved parents matched for age, gender, living area, marital status, number of children, and with a child born the same year as the deceased child was identified through the Swedish Population Register. To keep our procedures within the bounds specified by the Swedish 'law of secrecy', the identification of the suicide-bereaved and the matching of non-bereaved parents were done by the register holders and the researchers did not know whether the parents were bereaved or non-bereaved until they chose to reveal this themselves. We contacted all parents by means of an introductory letter followed by a telephone call after 2 weeks (Beskow *et al.* 1990; Dyregrov, 2004; Jorm *et al.* 2007; Eilegård *et al.* 2013). To minimize the risk of upsetting parents who were uncertain about the cause of death or believed that the cause of death was something other than suicide, we only included deaths registered as suicides [International Classification of Diseases, Tenth Revision

(ICD-10) code X60–84] and did not include deaths for which the cause was uncertain (ICD-10 code Y10–34). Although this may appear to be unusual, we had to consider the possibility that a few of the deaths had been erroneously classified as suicide. In the introductory letter we therefore addressed the parents as 'someone who has lost a son or daughter in a sudden death' and someone 'who has not lost a son or daughter' and emphasized that the questionnaires were developed together with suicide-bereaved parents. We also forewarned participants that some of the questions could raise difficult emotions, although participants in similar studies often perceived the participation as valuable (Dyregrov, 2004; Jorm *et al.* 2007; Dyregrov *et al.* 2010). In the introductory letter we emphasized that participation was voluntary and informed about the possibility to end participation at any time without further explanation (Jorm *et al.* 2007). The researchers' names and telephone numbers, one of which was toll free, were listed and the parents were encouraged to contact us with questions or if they needed support at any time during the study. For ethical reasons we made it easy to decline without any need for personal contact by indicating that they could decline by means of email, letter, text message or by leaving a message on an answering machine. We only sent around 50–100 introductory letters each week since we wanted to have time to attend to incoming and follow-up telephone calls. This time-frame also enabled us to stop the data collection if our research were to prove to be harmful to the participants in any way. During the whole study we avoided contact on official holidays and weeks containing birthdays, name days and the date of the death (fictional for the non-bereaved). We used a tailor-made database to enable a safe and systematic data collection. All events as well as the parents' comments were carefully noted and registered in the database.

The telephone calls were made by an experienced research assistant or by the first author (P.O.) who is a registered nurse specialized in psychiatry (Omerov *et al.* 2013). To avoid distress and personal intrusion, all calls were made using a sensitive 'step-by-step approach', meaning that we started with general questions and were responsive to any indication that it was time to stop probing. A denial was accepted immediately without challenging the decision or trying to persuade the parent to participate. Spontaneous motivations for the denials were noted and sorted according to categories established in the pilot study (Omerov *et al.* 2013). Usually, we started the telephone conversation by asking the parent if he or she had read the introductory letter and whether the parent had any questions. If the informant did not decline or did agree to participate directly, which was the common case, we asked if he or she wanted to look at a questionnaire. If the answer was yes, we then asked if he or she had lost a son or daughter. If this was the case, we explained that the questionnaire had been developed in cooperation with suicide-bereaved parents, which often resulted in a comment about their own son or daughter's cause of death. A few parents told us that the cause of death was unknown to them or that their son or daughter had died in an accident or had been murdered. The callers were always prepared to listen for as long a time as was needed (Dyregrov, 2004). All parents that expressed a need for support were offered the chance to talk with the first author who has long experience working with traumatized patients and suicide-related issues. A few parents needed further professional intervention and were either aided in obtaining appropriate help or were offered the chance to speak with the last author (U.N.) who is a physician specialized in psychiatry as well as suicidology. We emphasized that participation could be ended at any time without further explanation and also informed the parent about the possibility to answer the questionnaire anonymously. At each telephone call we asked for consent to call again if the parent had not returned the questionnaire within a time-frame that we had agreed upon (Omerov *et al.* 2013).

Results

Participants

The questionnaires were returned by 666 of the 915 (73%) suicide-bereaved, and 377 of the 508 (74%) non-bereaved parents (Table 2). The mean length of time for completing the questionnaire was 38 days (median 19 days). The mean answering rate for the main questions was 98% (data not shown in the table). A majority, 633 of 666 (95%) bereaved and 347 of 377 (92%) non-bereaved parents, answered that they thought that the study was valuable, and 604 of 666 (91%) and 287 of 377 (76%) that they would recommend another parent to participate. We found that 334 of 666 (50%) and 104 of 377 (28%) reported being positively affected by their participation, whereas 70 of 666 (11%) and three of 377 (1%) reported being negatively affected (Table 3). Of the suicide-bereaved that reported being negatively affected, 51 referred to painful memories in their written comments and 10 wrote that they felt sad or depressed. Some commented that these feelings were not necessarily bad for them and 36 of 70 (51%) reported being both negatively and positively affected by their participation (data not shown in the table). Among the suicide-bereaved parents that reported being

Table 2. *Participation and characteristics of suicide bereaved and non-bereaved parents*

	Suicide-bereaved[a]	Non-bereaved[b]
Eligible parents, *n* (%)	915 (100)	508 (100)
Fathers	424 (46)	232 (46)
Mothers	491 (54)	276 (54)
Did not provide information, *n* (%)	249 (27)	131 (26)
Not reachable	8 (<1)	5 (1)
Declined participation	125 (14)	88 (17)
Agreed but did not participate	116 (13)	38 (7)
Provided information, *n* (%)	666 (73)	377 (74)
Fathers	283 (67)	166 (72)
Mothers	383 (78)	211 (76)
Characteristics of participating parents, *n*	666	377
Gender, *n* (%)		
Fathers	283 (42)	166 (44)
Mothers	383 (58)	211 (56)
Median age, years (interquartile range)		
Fathers	58 (53–62)	59 (54–62)
Mothers	55 (51–59)	54 (50–59)
Year of child's death, *n* (%)		Not applicable
2004	162 (24)	
2005	174 (26)	
2006	169 (25)	
2007	161 (24)	
Median age of deceased child, years (interquartile range)	23 (20–27)	Not applicable
Gender of deceased child, *n* (%)		Not applicable
Male	462 (69)	
Female	204 (31)	
Children, *n* (%)[c]		
One child	71 (11)	43 (11)
Two children	241 (36)	139 (37)
Three or more children	350 (53)	193 (51)
Not stated	4 (<1)	2 (<1)
Biological children	635 (95)	369 (98)
Non-biological children	31 (5)	7 (2)
Not stated	0 (0)	1 (<1)
Family constellation at time of study, *n* (%)		
Living with a partner	477 (72)	271 (72)
Has a partner but lives alone	44 (7)	28 (7)
Single	121 (18)	67 (18)
Widow, widower	18 (3)	11 (3)
Not stated	6 (<1)	0 (0)
Residence area, *n* (%)		
Rural	162 (24)	77 (20)
Village (population <10 000)	153 (23)	97 (26)
Small town (population <50 000)	128 (19)	73 (19)
Town (population <200 000)	117 (18)	62 (16)
Larger town (population >200 000)	97 (15)	68 (18)
Not stated	9 (1)	0 (0)
Country of birth, *n* (%)		
Born in Sweden	629 (94)	371 (98)
Born in other Nordic country	36 (6)	6 (2)
Not stated	1 (<1)	0 (0)

Table 2 (*cont.*)

	Suicide-bereaved[a]	Non-bereaved[b]
Level of education, *n* (%)		
Less than primary school	5 (<1)	2 (<1)
Primary school	141 (21)	71 (19)
Secondary school	271 (41)	158 (42)
Higher education (<3 years)	82 (12)	55 (15)
Higher education (>3 years)	159 (24)	91 (24)
Not stated	8 (1)	0 (0)
Source of income, *n* (%)		
Employed or self-employed	498 (75)	303 (80)
Old-age pension	59 (9)	38 (10)
Disability pension	61 (9)	21 (6)
Unemployment fund	25 (4)	6 (2)
Study allowance	4 (1)	0 (0)
Social security	3 (0)	0 (0)
Other	9 (1)	9 (2)
Not stated	7 (1)	0 (0)
Annual income in Swedish crowns, *n* (%)		
0–99 000	34 (5)	10 (3)
100 000–199 000	120 (18)	64 (17)
200 000–399 000	388 (58)	240 (64)
400 000 or more	109 (16)	59 (16)
Not stated	15 (2)	4 (1)
Religion, *n* (%)		
Do not believe in God	355 (53)	216 (57)
Believes in God	287 (43)	150 (40)
Not stated	24 (4)	11 (3)

[a] Parents who, according to the registers, had lost a son or daughter to suicide, age 15–30 years, between 2004 and 2007. Parents born outside a Nordic country, without a registered address and telephone number, who could not speak Swedish, or had lost more than one child were excluded.

[b] Non-bereaved parents matched for gender, age, marital status, index child, number of children and residence area. The inclusion criteria were identical, except that they were not allowed to have lost a child.

[c] The suicide-bereaved parents' dead child is included in the figures.

negatively affected, 14 of 69 (20%) were moderately to severely depressed (score 10 or more) according to the PHQ-9. In total, 115 of 665 (18%) suicide-bereaved and 28 of 374 (8%) non-bereaved parents were moderately to severely depressed (score 10 or more) according to the PHQ-9 (data not shown in the table). Only one suicide-bereaved and one non-bereaved parent answered that they thought that the negative effect might last. In all, 25 of 666 (4%) bereaved and 17 of 377 (5%) non-bereaved parents answered that they regretted their participation. Of the 25 suicide-bereaved, 14 commented on this answer; eight referred to painful memories and sadness; five to too many questions and one parent perceived the questionnaire as impersonal. Of the 17 non-bereaved parents, four commented on their answers; one referred to ongoing cancer disease, one that she had not lost a child, one to research participation in general and one to low mood. A total of 265 of the suicide-bereaved parents commented in response to the question on being positively affected by participation. The comments fit predominantly into three categories: (i) gratitude for the opportunity to relate experiences and for interest in the child, situation and subject; (ii) hope that relating their experiences might help others in a similar situation and improve care provision; and (iii) experience of being helped by working through memories and feelings raised by answering the questionnaire. The non-bereaved parents wrote 78 comments in reply to the question and most of them referred to gratefulness for helping others and gratefulness for having their child and their health.

Table 3. *Experience of research participation*

	Suicide-bereaved parents	Non-bereaved parents
Do you think it's valuable to conduct such a survey?		
No	8/666 (1.2)	12/377 (3.2)
Yes	633/666 (95.0)	347/377 (92.0)
Yes, a little	38/666 (5.7)	60/377 (15.9)
Yes, rather much	112/666 (16.8)	135/377 (35.8)
Yes, very much	483/666 (72.5)	152/377 (40.2)
Not stated	25/666 (3.8)	18/377 (4.8)
Do you think this survey has had a negative effect on you?		
No	574/666 (86.2)	363/377 (96.3)
Yes	70/666 (10.5)	3/377 (0.8)
Not stated	22/666 (3.3)	11/377 (2.9)
If yes, do you think this negative effect will last?		
No	65/70 (92.9)	2/3 (66.7)
Yes	1/70 (1.4)	1/3 (33.3)
Not stated	4/70 (5.7)	0/3 (0)
Do you think this survey has had a positive effect on you?		
No	293/666 (44.0)	256/377 (67.9)
Yes	334/666 (50.2)	104/377 (27.6)
Not stated	39/666 (5.9)	17/377 (4.5)
If yes, do you think this positive effect will last?		
No	77/334 (23.0)	34/104 (32.7)
Yes	198/334 (59.3)	55/104 (52.9)
Not stated	59/334 (17.7)	15/104 (14.4)
Would you recommend another parent to participate in this study?		
No	37/666 (5.6)	72/377 (19.1)
Yes	604/666 (90.7)	287/377 (76.1)
Yes, a little	102/666 (15.3)	96/377(25.5)
Yes, rather much	166/666 (24.9)	95/377 (25.2)
Yes, very much	336/666 (50.5)	96/377 (25.5)
Not stated	25/666 (3.8)	18/377 (4.8)
Do you regret participating in this study?		
No	635/666 (95.3)	349/377 (92.6)
Yes	25/666 (3.8)	17/377 (4.5)
Yes, a little	20/666 (3.0)	10/377 (2.7)
Yes, rather much	4/666 (0.6)	0/377 (0)
Yes, very much	1/666 (0.2)	7/377 (1.9)
Not stated	6/666 (0.9)	11/377 (2.9)

Data are given as number of participants/total number of participants (percentage).

Non-participants

A total of 13 parents could not be reached by telephone or email; eight of them were suicide-bereaved and five non-bereaved, according to the registries (Fig. 1). Most of the 213 parents that declined participation did so in a friendly manner without hesitation (data not shown in the table). Of those who spontaneously gave a motivation to their decision not to participate, 26 were categorized as due to 'distress or ill-health' of which 22 referred to ongoing psychological distress or ill-health and four to somatic diseases or conditions. Similar reasons were given for the 22 cases in which participation was declined by another person. In all, 21 parents said that they did not participate in research as a principle and seven persons referred to 'lack of time'. Of those who did not want to participate, six persons stated that their son or daughter had died from causes other than suicide (Fig. 1). Several of the parents that declined regarded the research group as connected to the healthcare system and expressed disappointment over the health care that the child had received. Professional encounters, both before and after the suicide, that were perceived as hurtful were also commonly described.

Offended non-participants

In total, we concluded that eight parents had been offended by the contact *per se*. Of these, six persons denied participation by expressing irritation or anger; two persons were initially shocked and distressed that the cause of death had been attributed to suicide; one person wanted our help to reinvestigate the cause of death and later expressed gratitude over the help he received. The other person accepted our offer of a follow-up call but later chose to communicate that she felt better through her spouse. The spouse, who chose to participate in the study, said that despite her negative reaction, he believed that the contact had had a positive overall effect on their family.

Agreed to participate but ended participation

In total, 31 of the bereaved parents agreed to participate and received a questionnaire but ended their participation due to 'distress or ill-health'; two of them referred to somatic diseases and the rest to psychological distress or ill-health that had started before the contact with us (Fig. 1). Around half of these parents received support over the telephone with the first author, and a handful were also referred to the last author. Several had ongoing contact with other health professionals and others were supported in finding a suitable contact. A few participants with an ongoing depression or an anxiety disorder were encouraged to end their participation after describing how they had struggled but failed to answer the questions. Around 50 parents ended their participation without giving any explanation and around 50 referred to 'lack of time' or a 'complicated life situation'. Some parents thought that the questionnaire was too extensive and a few that it did not match their special circumstances. A few participants or relatives to the participants perceived the questions as being too personal. Some of the parents (15 in all) claimed to have returned their questionnaires, but these could not be found (Fig. 1).

Discussion

We investigated how 666 suicide-bereaved and 377 non-bereaved parents perceived their research participation in an extensive population-based survey. A minority of the participants answered that they were negatively affected by the participation and in total two out of 1043 stated that they thought the negative effects might last; one was bereaved, the other was not. On the other hand, positive experiences were widely expressed and 94% of the parents thought that the study was valuable.

Our findings correspond with Eilegård *et al.* (2013) who found that none of 168 bereaved siblings thought that their research participation would affect them negatively in the long term. The siblings had lost a brother or sister to cancer and answered a survey 2–9 years after their loss. This population-based survey was based on the same methodology as our survey and used identical questions to measure long-term experience of research participation. As in previous studies, only a minority of the participants reported being negatively affected at the time of participation and compilation of the findings from previous studies suggests that negative feelings rapidly decrease with time (Runeson & Beskow, 1991; Kreicbergs *et al.* 2004*b*; Jorm *et al.* 2007; Legerski & Bunnell, 2010). However, a significant group of parents, especially among the suicide-bereaved, agreed to participate but then withdrew, several referring to distress or ill-health. It is our impression that the motivation to participate was stronger among the suicide-bereaved parents in comparison with the non-bereaved. At the same time, psychological morbidity prior to participation was higher among the suicide-bereaved who also received a longer and more emotionally-challenging questionnaire. We spoke to nearly every one of the suicide-bereaved that withdrew their participation and no one expressed that they regretted their initial consent to participate. Although no one concluded that their distress was caused by their participation, several parents said that answering the questions was too much of a struggle in their present state of psychological ill-health. One may hypothesize that if these parents had fulfilled their participation, the percentage of negatively affected persons would have been higher. We also found that some parents that were eager to continue despite severe distress needed encouragement to end their participation, which emphasizes the importance of having a personal contact.

As in previous investigations, the majority of our participants found their participation valuable (Runeson & Beskow, 1991; Dyregrov, 2004; Kreicbergs *et al.* 2004*b*; Jorm *et al.* 2007; Legerski & Bunnell, 2010; Eilegård *et al.* 2013). Several parents

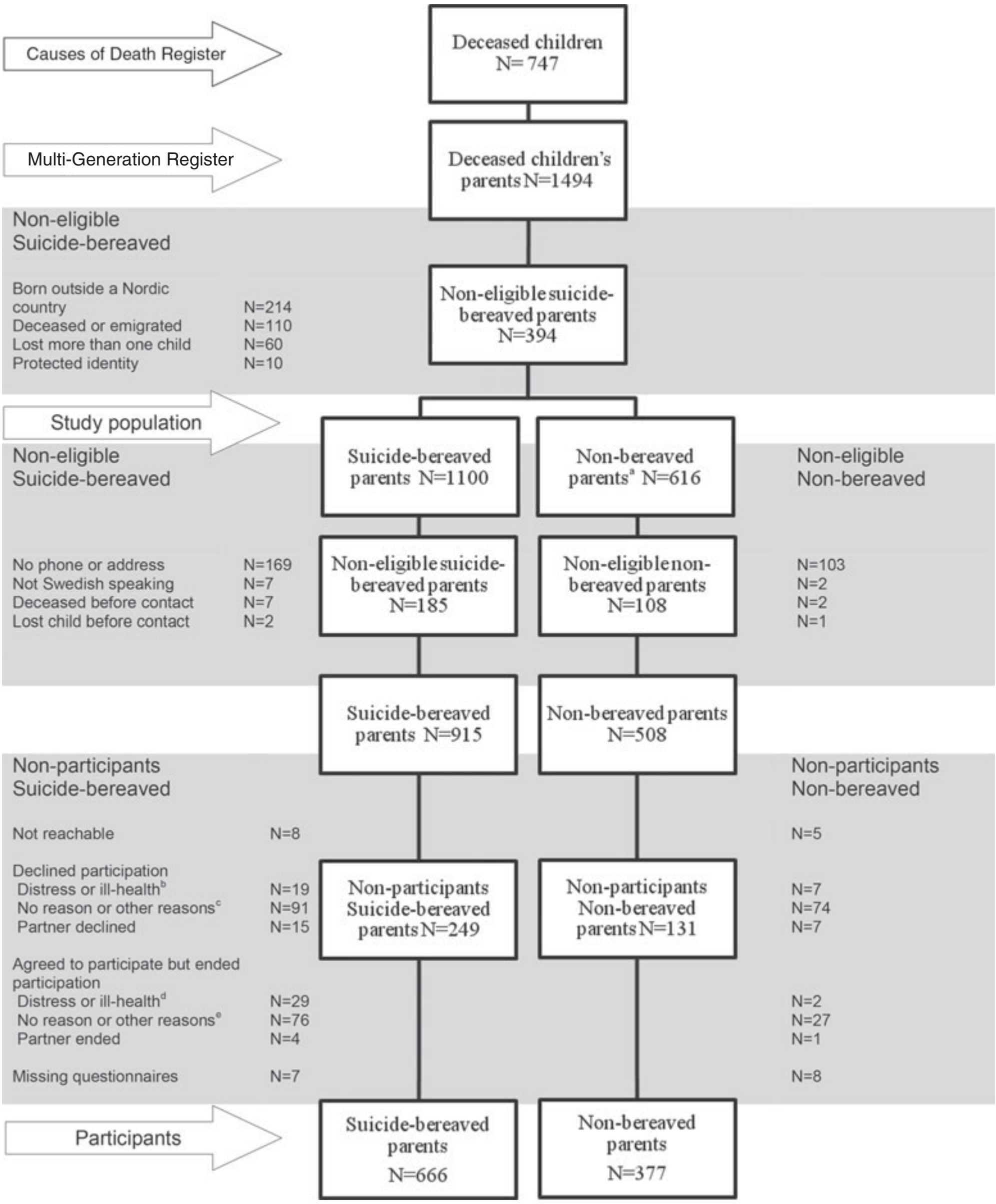

Fig. 1. Participation and non-participation among suicide-bereaved and non-bereaved parents. All information in this figure is based on information from the registries (only group level) or from the parents themselves. Due to the requirements of the Swedish 'act of secrecy' the researchers did not know if the parent was bereaved or non-bereaved until he or she chose to reveal this personally. [a] The non-bereaved parents were matched with the suicide-bereaved parents in a ratio of 2:1 on the following variables: marital status, age, gender, living area and number of children. All the non-bereaved participants had a child born the same year as the deceased child's age. All fulfilled the same inclusion criteria as the suicide-bereaved parents: was born in a Nordic country and had a listed telephone number and address. [b] A total of 26 parents declined due to psychological distress or ill-health and four to somatic disease or conditions. The same reasons could be found among the partners who declined. [c] Other reasons were mainly related to unwillingness to participate in research *per se* (n=22), 'lack of time' (n=7) or the cause of death being something other than suicide (n=6). [d] In all, 31 parents ended participation due to psychological distress or ill-health and two to a somatic disease or conditions. The same reasons could be found among the partners who declined. [e] Around 50 parents ended their participation without given reasons and about 50 referred to 'lack of time' or a 'complicated life situation'.

expressed that the personal telephone contact was valuable and welcomed the opportunity to tell about their experiences. The opportunity to disseminate knowledge about their situation was also emphasized as positive in their written comments. The suicide-bereaved parents also wrote that going through the questions was helpful since it aided them to remember and work through emotions. At the same time, 'painful memories' and 'feelings of sadness' were the most common motivations to being negatively affected or regretting participation. This shows the value of letting the respondents themselves rate if they were negatively affected or not since the respondents are the only ones that can put this question in a context of their whole situation. The wording 'negative or positive' might, however, be misleading since immediate undesirable reactions may be beneficial in the long term, a possibility that was also suggested by the participants themselves (Dyregrov, 2004; Jorm *et al.* 2007; Dyregrov *et al.* 2010). Some parents also referred to practical issues when they rated being 'negatively affected' and if they regretted their research participation, which shows that different evaluation criteria were used when answering the questions. Our control group consisted of matched parents who had not lost a child. Their shortened questionnaires involved a few questions regarding their experience of death and suicide; otherwise they were not asked to recall any traumatic events. The prevalence of negatively affected parents in the control population suggests that some of the effects cannot be explained by answering questions about a specific trauma, which is also supported by previous research (Jorm *et al.* 2007).

Our impression was that most parents did not have a problem with either declining or accepting participation, a finding supported by previous studies (Jorm *et al.* 2007; Dyregrov *et al.* 2011). The introduction letter gave the presumptive participant time to consider and to prepare his or her decision before the telephone call. We also made it easy to decline participation without personal contact. It is sometimes argued that it is more ethical to leave it up to the presumptive participant to initiate the contact after receiving the information letter, but this dramatically decreases the response rate (Beskow *et al.* 1990; Eilegård *et al.* 2013). Also, a personal telephone call enables the researchers to respond to reactions to the contact. In our study, eight of 1423 parents expressed distress related to the contact. In two cases the distress was later transformed into gratitude for the help received. We believe that our study design that thoroughly considered every detail in the written and personal contact reduced the number of distressed persons. However, we do not know anything about the 13 parents that could not be reached. One may hypothesize that the number of parents being initially distressed would have been higher if we had included the causes of death that were registered as uncertain, although we know that most of these are suicides. It is also possible that some of the ones that chose not to participate without giving an explanation were distressed about the contact. It is important to note that our contact provided essential and sometimes crucial help for several non-participants and participants that suffered from psychological distress or ill-health.

Our study has several strengths: one is the large sample of suicide-bereaved parents and matched controls, all identified through nationwide high-quality registers (Ludvigsson *et al.* 2009); another is the high participation rate (Table 2). We addressed the threats to validity by the hierarchical step-model (Steineck *et al.* 2006). First, we had to consider possible confounding factors. We did this by matching the suicide-bereaved with the non-bereaved parents on sociodemographic variables and by measuring other possible confounding factors in the questionnaire (Omerov *et al.* 2013). We found that the factors we matched for as well as the measured ones showed high concordance among the groups of respondents (Table 2). Second, we used several measures to reach a sufficiently high participation rate. In total, 73% parents answered our questionnaire, which should be high enough to avoid systematic errors related to misrepresentation. Third, in order to reduce the risk of misclassification we tested all questions in our thorough preparatory study with parents from our study population (Charlton, 2000; Edwards *et al.* 2009; Alderman & Salem, 2010; Omerov *et al.* 2013). Our study also has limitations. In all, 26% of the eligible parents did not answer the questionnaire and we do not know how they would have answered the questions of interest and whether their participation would have affected our findings. We know that several of the suicide-bereaved decided not to participate because of psychological distress or morbidity and that some declined participation to avoid additional distress. One may hypothesize that this group would be more affected by the participation which would lead to an underestimation of the ones reporting being both negatively and positively affected by the participation (Legerski & Bunnell, 2010). We made the choice not to collect longitudinal data, since previous studies show that it is difficult to maintain sufficient response rates in these kind of surveys (Clark, 2001). This, and the opportunity of answering anonymously, disabled us from measuring the participants' actual long-term experience of research participation. Instead, we had to ask the participants themselves if they thought that any negative or positive effect of their participation would last. Only a minority reported being negatively affected by the research participation and previous studies suggest that it is unlikely that persons that were not negatively affected initially would be that later on as a consequence of research participation (Legerski & Bunnell, 2010). The primary manifestation of research participation and distress might be universal; still, generalizability to other suicide-bereaved populations may be compromised by culture-specific issues.

Conclusions

Our findings suggest, given that the study design is ethically and methodologically sound, that suicide-bereaved parents should be included in research since the benefits clearly outnumber the risks. Almost all parents found the study valuable and the need for the research was strongly emphasized. Also of utmost importance, several non-participants and participants described severe psychological suffering and received help because of the contact. The high prevalence of depression among the bereaved suggests that professional interventions might be useful to reduce psychological morbidity. However, evidence to guide these interventions is sparse and more research is needed. This conclusion has to be weighed against the finding that a few parents did express distress related to the contact and participation.

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Declaration of Interest

None.

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Psychological morbidity among suicide-bereaved and non-bereaved parents: a nationwide population survey

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ABSTRACT

Objective: To determine how psychological premorbidity affects the risk of depression in parents who lost a child through suicide.

Design: Population-based survey.

Setting: Sweden, between 2009 and 2010.

Participants: All parents who lost a child, age 15–30, through suicide between 2004 and 2007 according to National population registries. Non-bereaved parents matched for age, sex, living area, marital status, number of children. Exclusion criteria: born outside a Nordic country, not Swedish speaking, contact details missing. Participants: 666 of 915 (73%) suicide-bereaved and 377 of 508 (74%) non-bereaved parents.

Main outcome measures: Depression measured by the nine-item depression scale of the Patient Health Questionnaire (PHQ-9) and study-specific questions to assess psychological premorbidity and experience of the child's presuicidal morbidity.

Results: In all, 94 (14%) suicide-bereaved and 51 (14%) non-bereaved parents (relative risk 1.0; 95% CI 0.8 to 1.4) had received their first treatment for psychological problems or had been given a psychiatric diagnosis more than 10 years earlier. The prevalence of moderate-to-severe depression was 115 (18%) in suicide-bereaved versus 28 (7%) in non-bereaved parents (RR 2.3; 95% CI 1.6 to 3.5). For those without psychological premorbidity, the relative risk was 2.3 (95% CI 1.4 to 3.6). 339 (51%) suicide-bereaved parents expressed worry over the child's psychological health during the month preceding the suicide and 259 (39%) had anticipated the suicide.

Conclusions: In parents who lost a child through suicide in Sweden we did not find a higher prevalence of long-term psychological premorbidity than among parents who had not lost a child; the more than twofold risk of depression among the bereaved can probably be explained by the suicide and the stressful time preceding the suicide.

ARTICLE SUMMARY

Article focus

- Depression is common in parents who have lost a child through suicide and the condition might become long-lasting and life-threatening.
- As yet, we do not know to what extent psychological premorbidity influences the outcomes of the bereavement.
- Previous studies have not disentangled long-term psychological premorbidity such as psychiatric diseases from short-term psychological premorbidity due to stress related to parenting a suicidal child.

Key messages

- Our study suggests that suicide-bereaved and non-bereaved parents' prevalence of long-term psychological premorbidity does not differ if measured more than 10 years prior to the suicide and that the more than twofold risk of depression in bereaved parents can be found regardless of long-term psychological premorbidity.
- The elevated risk of depression can probably be explained by the suicide and the stressful time preceding the suicide rather than psychological premorbidity. This adds important information for further intervention studies on the treatment of grief-related depression.

Strengths and limitations of this study

- The study relies on a large sample of suicide-bereaved parents and matched controls, all identified through nationwide registers. The data collection includes psychometric measurements as well as study-specific data that cannot be retrieved from patient registers. The participation rate was high among suicide-bereaved and non-bereaved men and women.
- The questions regarding psychological premorbidity cover a large time-span and the answers might be affected by recall-induced problems. The questions do not measure the severity of the psychological premorbidity.

INTRODUCTION

Suicide-bereaved parents are at risk of developing mental disorders that might become long-lasting and life-threatening.[1–6] The bereavement-outcome is affected by factors related to the traumatic loss and to factors related to the bereaved individual.[7–11]

Suicide-bereaved family members may have an increased vulnerability for psychological morbidity due to genetic and environmental factors such as psychiatric illness, personality traits and suicidal behaviour.[12–14] The majority of suicide-bereaved parents do not suffer from mental disorders prior to the child's suicide, but there is a subgroup that does.[15 16] In a recent Canadian register study, previous psychological morbidity was found to be more prevalent among suicide-bereaved parents than non-bereaved control parents[16]; we do not know if these results are relevant to European communities.

Grief-related depression might be successfully treated.[17] The occurrence and aetiology of depression of suicide-bereaved parents are, however, yet to be studied carefully. In this population-based study, we examine the long-term risk of depression among suicide-bereaved and non-bereaved parents, with and without psychological premorbidity. We hypothesised that suicide-bereaved parents had a higher prevalence of psychological premorbidity in comparison with non-bereaved parents. We also examine the suicide-bereaved parents experience of the child's presuicidal morbidity during the year preceding the suicide. The parents were identified by nationwide registries and data were collected by a detailed questionnaire.[18]

METHODS

Subjects

We identified all individuals, 15–30 years old, who died through suicide (ICD 10: X60–X84) between 2004 and 2007 and whose deaths were registered in the nationwide Swedish Cause of Death Register. We thereafter used the unique personal identity numbers and the nationwide Multigeneration Register to identify the bereaved parents.[19] To be included in the study, the parent had to be born in one of the Nordic countries, be able to communicate in Swedish and have an identifiable address and telephone number. Furthermore, parents that had lost more than one child were excluded. A random sample of non-bereaved parents matched for age, sex, living area, marital status, number of children and with a child that was born in the same year as the deceased child was identified through the Swedish Population Register. The ratio of one non-bereaved to two suicide-bereaved gave sufficient statistical power to test our hypotheses regarding depression and anxiety according to a power calculation. The inclusion criteria for the non-bereaved parents were identical to those for the bereaved parents, except that they were not allowed to have lost a child. In total, 915 suicide-bereaved and 508 non-bereaved parents were identified as eligible. The participants gave informed consent before taking part.

Data collection and measurements

We developed the study design from routines established by the Division of Clinical Cancer Epidemiology.[18 20–22] Our study-specific questionnaires were constructed in a preparatory study using mixed methods including 46 suicide-bereaved persons. In this study, we tested all questions, including the psychometric scales described below.[18] We used four questions with a follow-up question to measure psychological premorbidity: (1) 'Have you ever received treatment for psychological problems such as depression, anxiety, psychosis or personality disorder?' Treatment was defined as treatment prescribed by a physician, for example, medication, electroconvulsive therapy (ECT) or conversational therapy. 'If yes, when did you receive your first treatment?' (2) 'Have you ever been given a psychiatric diagnosis, for example, depression, panic disorder, psychosis or personality disorder?' 'If yes, when were you given your first diagnosis?' (3) 'Have you during a period of your life medicated against anxiety?' 'If yes, when did you take your first medication?' (4) 'Have you during a period of your life medicated against low mood or depression?' 'If yes, when did you take your first medication?' The answer categories were 'more than 10 years earlier' and 'during the last 10 years' for the non-bereaved and 'more than 10 years earlier', 'during the last 10 years, before my child's death' and 'during the last 10 years, after my child's death' for the bereaved. We used psychometric scales for three of our psychological outcomes: the two-item Generalised Anxiety Disorder scale (GAD-2),[23] the nine-item depression scale of the Patient Health Questionnaire (PHQ-9)[24] and the Alcohol Use Disorders Identification Test (AUDIT).[25] Symptoms of anxiety and depression were also assessed by questions based on the Diagnostic and Statistical Manual Fourth Edition (DSM-IV) criteria.[26] We contacted all eligible parents by sending them an introductory letter and thereafter by telephone and asked for consent to send a questionnaire. We started the data collection in August 2009 and the last questionnaire was returned in December 2010.[18]

Statistical analysis

We tested for differences in characteristics using Pearson's χ^2 test and Wilcoxon-Mann-Whitney's test. We dichotomised scores derived from the psychometric scales using recommended cut-offs.[27–29] We used log-binomial regression to calculate the relative risks (RR) shown in tables 1–4. We thereafter present RR of the different outcomes adjusting for potential confounders, one variable at a time. For modelling involving more than two explanatory variables, we had to use OR estimated through logistic regression, since log-binomial regression did not converge and failed to produce estimates. We performed a variable selection among the possible confounders, using logistic regression with forward selection in order to identify those variables most strongly related to the main outcomes (PHQ-9, GAD-2, AUDIT) in each group. We made the selection among parents without any psychological premorbidity according to answers to the four questions asked, separately within the groups of suicide-bereaved and non-

Table 1 History of psychological premorbidity among suicide-bereaved and non-bereaved parents

Psychological morbidity with first appearance more than 10 years earlier	Suicide-bereaved Number/total number (%)	Non-bereaved Number/total number (%)	Relative risks (CI 95%)
Psychological problems*,†	71/659 (11)	38/373 (10)	1.0 (0.7 to 1.5)
Psychiatric diagnosis†,‡	45/651 (7)	18/373 (5)	1.4 (0.8 to 2.4)
Medication against anxiety†,§	52/657 (8)	24/377 (6)	1.2 (0.8 to 2.0)
Medication against low mood †,¶	61/655 (9)	23/373 (6)	1.5 (1.0** to 2.4)
Any of the above††	94/663 (14)	51/377 (14)	1.0 (0.8 to 1.4)

*Have you ever received treatment for psychological problems such as depression, anxiety, psychosis or personality disorder? (treatment was defined as treatment prescribed by a physician, eg, medication, electroconvulsive therapy (ECT) or conversational therapy). If yes, when did you receive your first treatment?

†The answer categories were ‘more than 10 years earlier’ and ‘during the last 10 years’ for the non-bereaved and ‘more than 10 years earlier’, ‘during the last 10 years, before my child’s death’ and ‘during the last 10 years, after my child’s death’ for the bereaved.

‡Have you ever been given a psychiatric diagnosis, for example, depression, panic disorder, psychosis or personality disorder? If yes, when were you given your first diagnosis?

§Have you during a period of your life medicated against anxiety? If yes, when did you take your first medication?

¶Have you during a period of your life medicated against low mood or depression? If yes, when did you take your first medication?

**The exact confidence limit is 0.95.

††Referred to as with premorbidity in table 3.

bereaved parents. Since we wanted to maximise the possibility of finding other explanatory factors that could potentially disprove the assumed effect of bereavement, we used a liberal inclusion criterion allowing variables up to the 15% significance level entry. For those with and without psychological premorbidity, we then formed one final model for each outcome utilising all variables that had been identified as associated with the outcome within at least one of the suicide-bereaved or non-bereaved groups and report the resulting adjusted ORs.

Table 2 Psychological morbidity among suicide-bereaved and non-bereaved parents

	Suicide-bereaved Number/total number (%)	Non-bereaved Number/total number (%)	Relative risks RR (CI 95%)
Anxiety and depressive symptoms			
Single item questions*			
Persisting anxiety†	41/664 (6)	4/377 (1)	5.8 (2.1 to 16.1)
Anxiety attacks‡	53/664 (8)	5/377 (1)	6.0 (2.4 to14.9)
Awakening with anxiety during night‡	40/663 (6)	5/377 (1)	4.5 (1.8 to11.4)
Awakening with anxiety in the morning‡	46/664 (7)	2/377 (<1)	13.0 (3.2 to 53.5)
Low or depressive mood†	141/663 (21)	21/377 (6)	3.8 (2.5 to 5.9)
Psychometric scales			
Depression (PHQ-9)§	115/655 (18)	28/374 (7)	2.3 (1.6 to 3.5)
Anxiety (GAD-2)¶	139/658 (21)	22/374 (6)	3.6 (2.3 to 5.5)
Hazardous alcohol consumption (AUDIT) **	76/643 (12)	28/375 (7)	1.6 (1.0 to 2.4)
Medication single item questions* and PHQ-9			
Sleeping medication†	82/664 (12)	20/377 (5)	2.3 (1.5 to 3.7)
Antidepressant medication†	99/664 (15)	13/375 (3)	4.3 (2.4 to 7.6)
Anxiolytic medication†	49/662 (7)	8/375 (2)	3.5 (1.7 to 7.2)
Antidepressant medication and/or depression†,§	167/665 (25)	35/377 (9)	2.7 (1.9 to 3.8)

*Self-rated prevalence of symptoms during the preceding month with answering alternatives ranging from ‘no’, ‘yes occasionally’, ‘yes 1–3 times or days a week’, ‘yes 4–5 times or days a week’, and ‘yes 6–7 times or days a week’.

†‘Yes 1 day a week’ or more often.

‡‘Yes 1 time a week’ or more often.

§The nine-item depression scale (PHQ-9), score 10 or higher (range from 0 to 27).The answering categories were slightly modified from ‘not at all’, ‘several days’, ‘more than half the days’, ‘nearly every day’ to ‘not at all’, ‘1–3 days a week’, ‘4–5 days a week’, and ‘6–7 days a week’, using the same system for scoring. The calculated scores were based on self-reported data.

¶The two-item Generalised Anxiety Disorder scale (GAD-2) score 2 or higher (range from 0 to 6). The answering categories were slightly modified as described above, using the same system for scoring. The calculated scores were based on self-reported data.

**The Alcohol Use Disorders Identification Test (AUDIT) scores 8 or higher (range from 0 to 40).The calculated scores were based on self-reported data.

AUDIT,alcohol use disorders identification test; GAD, generalised anxiety disorder; PHQ, Patient Health Questionnaire.

Table 3 Unadjusted and adjusted relative risks and ORs for outcome of depression (PHQ-9), anxiety (GAD-2) and hazardous alcohol consumption (AUDIT) among suicide-bereaved and non-bereaved parents, with and without psychological premorbidity

	RR (95% CI) adjusted for									OR (95% CI)	
	RR (95% CI) Unadjusted	Sex	Age	Residence area	Civil status	Level of education	Source of income	Physical activity	Social activity	Unadjusted	Adjusted for multiple*
With premorbidity†											
PHQ-9	2.6	2.6	2.8	2.5	2.5	2.5	2.3	2.3	2.2	3.5	2.8‡
≥10	(1.2 to 5.4)	(1.2 to 5.3)	(1.3 to 5.8)	(1.2 to 5.3)	(1.2 to 5.2)	(1.2 to 5.2)	(1.1 to 4.9)	(1.1 to 4.7)	(1.1 to 4.7)	(1.4 to 8.5)	(1.0 to 7.4)
GAD-2	3.8	3.8	3.7	3.7	3.5	3.8	3.3	3.4	4.2	5.5	4.7§
≥2	(1.6 to 9.0)	(1.6 to 9.0)	(1.5 to 9.0)	(1.6 to 9.0)	(1.5 to 8.4)	(1.6 to 9.1)	(1.4 to 8.0)	(1.4 to 8.2)	(1.6 to 11.0)	(2.0 to 15.0)	(1.5 to15.2)
AUDIT	1.4	1.4	1.2	1.5	1.3	1.4	1.6	1.1	1.2	1.5	1.0¶
≥8	(0.5 to 3.8)	(0.5 to 3.6)	(0.5 to 3.3)	(0.6 to 3.8)	(0.5 to 3.5)	(0.5 to 3.7)	(0.6 to 4.2)	(0.4 to 3.1)	(0.4 to 3.2)	(0.5 to 4.5)	(0.3 to 3.5)
Without premorbidity											
PHQ-9	2.3	2.2	2.3	2.3	2.3	2.3	2.1	2.3	2.1	2.5	2.2‡
≥10	(1.4 to 3.6)	(1.4 to 3.5)	(1.4 to 3.6)	(1.4 to 3.6)	(1.4 to 3.6)	(1.4 to 3.6)	(1.3 to 3.4)	(1.5 to 3.6)	(1.3 to 3.3)	(1.5 to 4.0)	(1.3 to 3.7)
GAD-2	3.5	3.4	3.5	3.5	3.5	3.5	3.3	3.5	3.3	4.0	3.7§
≥2	(2.1 to 5.7)	(2.1 to 5.6)	(2.1 to 5.7)	(2.2 to 5.8)	(2.2 to 5.8)	(2.1 to 5.8)	(2.0 to 5.5)	(2.1 to 5.7)	(2.0 to 5.4)	(2.4 to 6.9)	(2.2 to 6.4)
AUDIT	1.6	1.6	1.6	1.6	1.6	1.6	1.6	1.6	1.5	1.7	1.7‡
≥8	(1.0 to 2.6)	(1.0 to 2.5)	(1.0 to 2.5)	(1.0 to 2.6)	(1.0 to 2.6)	(1.0 to 2.5)	(1.0 to 2.6)	(1.0 to 2.5)	(1.0 to 2.5)	(1.0 to 2.8)	(1.0 to 2.8)

*ORs adjusted for multiple variables selected by logistic regression with forward selection. The selection was done among those without psychological premorbidity, separately within the groups of bereaved and non-bereaved parents. The variables sex and age were forced into each model.

†Participants were categorised ‘With premorbidity’ if they, more than 10 years earlier: had their first treatment for psychological morbidity such as depression, anxiety, psychosis or personality disorder (treatment defined as treatment prescribed by a physician such as medication, electroconvulsive therapy (ECT) or conversational therapy) or, had been given their first psychiatric diagnosis such as depression, panic attacks, psychosis or personality disorder or used medication against anxiety or depression.

‡Variables selected in both bereaved and non-bereaved: (sex, age), source of income, social activity.

§Variables selected within the bereaved group: (sex, age), source of income, physical activity, social activity.

¶Variables selected in both bereaved and non-bereaved: (sex, age), source of income. Variables selected within the bereaved group: education, physical activity. Variables selected within the non-bereaved group: social activity.

AUDIT,alcohol Use disorders identification test; GAD, generalised anxiety disorder; PHQ, Patient Health Questionnaire; RR, relative risk.

Table 4 General health and well-being among suicide-bereaved and non-bereaved parents

	Suicide-bereaved Number/total number (%)	Non-bereaved Number/total number (%)	Relative risk (95% CI)
Quality of life during the last month*			
None to low	126/662 (19)	31/376 (8)	2.3 (1.6 to 3.3)
Well-being during the last month†			
No to yes, a little	228/660 (35)	53/377 (14)	2.5 (1.9 to 3.2)
Meaningful life during the last month‡			
No to yes, a little	190/658 (29)	37/377 (10)	2.9 (2.1 to 4.0)
Psychological health during the last month*			
None to low	136/662 (21)	29/377 (8)	2.7 (1.8 to 3.9)
Physical health during the last month*			
None to low	148/661 (22)	61/376 (16)	1.4 (1.0 to 1.8)
Feelings of guilt*			
Yes, 1–3 days a week or more	110/666 (17)	10/374 (3)	6.2 (3.3 to 11.7)
Fear of next-of-kin's death†			
Yes, 1–3 days a week or more	96/666 (14)	14/373 (4)	3.8 (2.2 to 6.6)

*Self-rated experiences during the preceding month with answering alternatives ranging from 'none', 'low', 'moderate' and 'high'.
†Self-reported prevalence of symptoms during the preceding month with answering alternatives ranging from 'no', 'yes occasionally', 'yes 1–3 days a week', 'yes 4–5 days a week', and 'yes 6–7 days a week'.
‡Self-rated experiences during the preceding month with answering alternatives ranging from 'no', 'yes a little', 'yes moderate', and 'yes much'.

We performed statistical tests at the 5% significance level, unless otherwise stated, and excluded individuals with missing data in each respective calculation. All statistical analyses were performed with the IBM SPSS Statistics software, V.19.0.

RESULTS

Participants

The questionnaires were returned by 666 of the 915 (73%) suicide-bereaved parents and 377 of the 508 (74%) non-bereaved parents. The suicide-bereaved and non-bereaved parents had similar background characteristics concerning: age, gender, residence area, family constellation, number of children, country of birth, level of education, source of income, yearly income and religiosity (table 5).

Primary outcomes

Psychological premorbidity, as measured by answers to single-item questions, did not differ significantly between the groups of suicide-bereaved and non-bereaved parents. In total 94 of 663 (14%) suicide-bereaved and 51 of 377 (14%) non-bereaved parents (RR 1.0; 95% CI 0.8 to 1.4) reported that they had received their first treatment for psychological problems or had been given a psychiatric diagnosis more than 10 years earlier, although the bereaved parents had somewhat higher prevalences for all the individual single-item questions (table 1).

Self-reported anxiety and depressive symptoms

The prevalence of moderate-to-severe depression, as measured by PHQ-9, was 115 of 655 (18%) among suicide-bereaved parents in comparison with 28 of 374 (7%) non-bereaved parents, resulting in a relative risk of 2.3 (95% CI 1.6 to 3.5; table 2). Split by sex, the prevalence of moderate-to-severe depression was 87 of 375 (23%) in suicide-bereaved mothers, 22 of 186 (12%) in non-bereaved mothers, 28 of 280 (10%) in suicide-bereaved fathers and 6 of 160 (4%) in non-bereaved fathers (data not shown in tables). When stratified according to psychological premorbidity, the prevalence of moderate-to-severe depression among those with premorbidity was 33 of 93 (35%) among the bereaved versus 7 of 51 (14%) among the non-bereaved (RR 2.6; 95% CI 1.2 to 5.4), while among those without premorbidity the corresponding prevalences were 82 of 560 (15%) among the bereaved versus 21 of 323 (7%) among the non-bereaved (RR 2.3; 95% CI 1.4 to 3.6). The statistically significant difference between bereaved and non-bereaved parents remained after adjusting for the following known risk-factors for depression: sex, age, residential area, civil status, level of education, source of income, physical activity and social activity (table 3).

Secondary outcomes

In comparison with the non-bereaved parents, the suicide-bereaved parents showed a higher prevalence of all negative outcomes, for which all differences except harmful alcohol consumption and physical health were statistically significant (tables 2–4). We found the risk of feelings of guilt (without a specified cause) to be more than six times higher among suicide-bereaved parents, and the risk of fear of next-of-kin's death to be about four times higher (table 4). Among the suicide-bereaved, 457 of 651 (70%) reported feelings of guilt for the child's death and 372 of 642 (58%) believed that they could have prevented the suicide. One of 4, 164 of 666 (25%) reported that their child had self-harmed

Table 5 Participation and characteristics of suicide-bereaved and non-bereaved parents

Participants	Suicide-bereaved n=666	Non-bereaved n=377	p Value
Sex—n (%)			0.630*
Fathers	283 (42)	166 (44)	
Mothers	383 (58)	211 (56)	
Age—year			
Fathers, median (IQR)	58 (53–62)	59 (54–62)	0.667†
Mothers, median (IQR)	55 (51–59)	54 (50–59)	0.161†
Children—n (%)‡			0.887*
One child	71 (11)	43 (11)	
Two children	241 (36)	139 (37)	
Three or more children	350 (53)	193 (51)	
Not stated	4 (<1)	2 (<1)	
Family constellation at time of study—n (%)			0.964*
Living with a partner	477 (72)	271 (72)	
Has partner but lives alone	44 (7)	28 (7)	
Single	121 (18)	67 (18)	
Widow, widower	18 (3)	11 (3)	
Not stated	6 (<1)	0 (0)	
Residence area—n (%)			0.365*
Rural	162 (24)	77 (20)	
Village (population <10 000)	153 (23)	97 (26)	
Small town (population <50 000)	128 (19)	73 (19)	
Town (population <200 000)	117 (18)	62 (16)	
Larger town (population >200 000)	97 (15)	68 (18)	
Not stated	9 (1)	0 (0)	
Country of birth—n (%)			0.003*
Born in Sweden	629 (94)	371 (98)	
Born in other Nordic country	36 (6)	6 (2)	
Not stated	1 (<1)	0 (0)	
Level of education—n (%)			0.625*
Elementary school or less	146 (22)	73 (19)	
Junior college	271 (41)	158 (42)	
College or university (<3 years)	82 (12)	55 (15)	
College or university (>3 years)	159 (24)	91 (24)	
Not stated	8 (1)	0 (0)	
Source of income—n (%)			0.060*
Employed or self-employed	498 (75)	303 (80)	
Old-age pension	59 (9)	38 (10)	
Disability pension	61 (9)	21 (6)	
Unemployment fund	25 (4)	6 (2)	
Other	16 (2)	9 (2)	
Not stated	7 (1)	0 (0)	
Yearly income in Swedish crowns—n (%)			0.189*
0–99 000 SEK	34 (5)	10 (3)	
100 000–199 000 SEK	120 (18)	64 (17)	
200 000–39 9000 SEK	388 (58)	240 (64)	
400 000 SEK or more	109 (16)	59 (16)	
Not stated	15 (2)	4 (1)	
Religion—n (%)			0.252*
Do not believe in God	355 (53)	216 (57)	
Believes in God	287 (43)	150 (40)	
Not stated	24 (4)	11 (3)	

*Pearson's χ^2 test.
†Wilcoxon-Mann-Whitney's test.
‡The suicide-bereaved parents' dead child is included in the figures.

and 150 of 666 (23%) that their child had tried to commit suicide during the year prior to the suicide. Seventy-nine of 666 (12%) also reported that their child had been in contact with the healthcare system several times as a result of suicide-attempts during the year prior to the suicide. One of 2, 339 of 666 (51%) were anxious over the child's psychological health and 294 of 666 (44%) had worried that their child might commit suicide during the month prior to the suicide. The suicide was perceived as somewhat expected by 259 of 666 (39%) parents and 424 of 666 (64%) believed that their child suffered from a psychiatric disease such as depression, anxiety disorder, personality disorder, psychosis or substance abuse. We found that the majority of suicides were made by violent means such as hanging, strangulation and suffocation (53%), by moving vehicles (13%), jumping from a height (7%) or by firearm discharge (7%) (data not shown in the tables).

DISCUSSION

In our nationwide survey of 666 suicide-bereaved and 377 non-bereaved parents, the bereaved did not have a higher prevalence of psychological premorbidity than the non-bereaved. However, the 14% of the bereaved with premorbidity more often reported several forms of premorbidity as compared to the 14% of the non-bereaved with premorbidity, possibly reflecting more severe afflictions. Among those without premorbidity, the bereaved parents had a more than twofold higher risk of moderate-to-severe depression 2–5 years after the loss, as measured by PHQ-9. The same was found for the more than threefold higher risk of anxiety, as measured by GAD-2 (table 3). We found an increased risk of depression and anxiety in both groups of suicide-bereaved, those with psychological premorbidity and those without.

Comparison with other studies

We found two population-based studies that investigated psychological premorbidity among suicide-bereaved and non-bereaved parents using registries on psychiatric admissions and diagnoses: Stenager and Qin's [15]study on 4142 individuals aged 9–35 years who committed suicide in Denmark during the period 1981 to 1997 and Bolton *et al*'s[16] study of 1415 suicide-bereaved parents in Manitoba, Canada between 1997 and 2007. Stenager and Qin[15] found that about 6% of the suicide-bereaved parents and about 3% of the non-bereaved controls had been admitted to a psychiatric hospital 10 years prior to the suicide and about 1.1% of the suicide-bereaved and 0.5% of the non-bereaved had been admitted within the past 3 years. In Bolton *et al*'s[16] study, 28% of the suicide-bereaved parents had had a mental disorder 2 years prior to the suicide, according to the registers. Bolton *et al* also showed that 15% of the suicide-bereaved parents had been diagnosed with depression 2 years prior to the suicide in comparison to 11% of the control parents who had been diagnosed with depression at the same time. Two years after the suicide, the prevalence rose to 31% among the suicide-bereaved parents, while the control parents' prevalence barely changed (10%). Bolton *et al* suggest that the suicide-bereaved parents have a premorbidity due to shared genetic and environmental factors as one part of the explanation, but they also recognise that the parents might have stress-related psychopathology due to factors that preceded the suicide. In our study, one of two suicide-bereaved parents had experienced anxiety over their child's psychological health and risk for suicide (44%) during the year prior to the suicide. Also, one of four had experienced that their child self-harmed and tried to commit suicide (23%), sometimes repeatedly during a long period of time prior to the suicide. To diminish the risk of capturing effects directly related to a stressful time of parenting during the years preceding the suicide, we chose to measure the debut of psychological premorbidity in the period ending more than 10 years before the suicide. The discrepancy in results might be related to the measurements as well as differences among populations. Our results are nationwide and self-reported. We included psychological treatments and psychotropic drugs prescribed by a physician in addition to psychiatric diagnoses, cases not always registered in inpatient or outpatient registers. One may hypothesise that cases of psychological morbidity reported in registers might be more severe and that severe psychiatric conditions are more prevalent among a subpopulation of the suicide-bereaved parents compared to controls.

Two longitudinal surveys found that while a history of depression is associated with recurrence of depression, one brief bereavement-related depressive episode is not.[30 31] In a sample from a longitudinal survey including the US general population,[30] 865 of 43 093 participants with a lifetime history of one brief bereavement-related depressive episode reported major depression 3 years later. In comparison, 2320 of 27 074 participants with no history of depression reported major depression at follow-up, resulting in a non-significant difference (RR 0.85; 95% CI 0.52 to 1.59). Similar results were found in Wakefield's longitudinal survey.[31] In contrast, our data suggest an elevated risk of depression 2–5 years after the loss among suicide-bereaved parents compared to non-bereaved parents, regardless of psychological premorbidity. One explanation for this discrepancy might be that our participants had lost a child and that death by suicide like other traumatic deaths often is associated with a particularly difficult grieving process.[32] This is supported by Kessling *et al*'s[2] case–control study on major life events and first-time admission for depression, which included 13 006 depressed patients and 260 108 age-matched and sex-matched controls. In this study, suicide of a family member was associated with 1.95 relative risk (95% CI 1.30 to 2.92) of being first-time admitted for depression, whereas death of a family member by causes other than suicide was associated with a non-significant relative risk of 1.11 (95% CI 0.91 to 1.35). We found a high risk of depression after parental bereavement in two register-based studies, both only including parents without previous psychiatric admissions. Li *et al*[3] followed more than 1 million parents during 1970 to 1999 and found that parents who lost a child, age 6 years or older, had a higher relative risk of being hospitalised for affective disorder; 2.72 (95% CI 1.54 to 4.81) among mothers and 1.85 (95% CI 0.59 to 5.75) among fathers. Kessling *et al*'s[2] case–control study stated that 26 of 13 006 individuals admitted with depression had experienced a child's suicide in comparison with 257 of 260 108 individuals who were not admitted, giving a relative risk of 1.95 (95% CI 1.30 to 2.92).

Strengths and limitations

Our study has several strengths: one is the large sample of suicide-bereaved parents and matched controls, all identified through nationwide high-quality registers. Another is the high participation rate among suicide-bereaved and non-bereaved men and women. The background characteristics among the respondents were remarkably similar among the bereaved and non-bereaved. We matched the group of suicide-bereaved with the group of non-bereaved on important, possible confounding sociodemographic variables and the responding groups were similar also on factors that we did not match for (table 5). Our study also has limitations. The questions regarding psychological premorbidity cover a large time-span and the answers might be affected by recall-induced problems due to time and informants' experiences. To reduce this risk, we asked specific questions about medication, psychiatric diagnoses and treatments prescribed by a physician rather than general questions about psychological morbidity. We also lack information about possible confounders related to personality, since questions on personality were perceived as difficult to grasp by the parents in the preparatory study.[18] We chose not to include personality inventories in the questionnaire due to their size. Our main outcome psychological morbidity is common in the general population and we wanted a demographically relevant group of parents for comparison of psychological premorbidity as well as current psychological morbidity. Using a comparison group of only non-bereaved parents not including parents bereaved by other death causes can be disputed. A disadvantage is that we cannot disentangle how much of the elevated psychological morbidity can be explained by loss of a son or daughter in general, and loss to suicide specifically. We lack information about the prevalence of psychological morbidity among non-participants and consequently about whether their participation would have affected our findings. We addressed the threats to validity by employing epidemiological methods as transferred to this field by the hierarchical step-model for study design, analysis and data interpretation.[33] Efforts to reduce the problem of misclassification included a thorough prestudy, developing and testing the questions and the psychometric scales in close collaboration with parents from the study population.[18] Our main outcomes were measured by psychometric as well as study-specific questions based on DSM-IV with similar results, and we have no reason to believe that the suicide-bereaved and non-bereaved differ systematically in their response to these questions. It is likely that the fundamental manifestations of grief are universal, but still, generalisation to other populations may be compromised by culture-specific issues.

CONCLUSION

Depression can be prevented and treated, but it is yet to be established if the methods used are as effective in the subgroups of parents who are suicide-bereaved and depressed. Our finding that the suicide-bereaved parents' prevalence of psychological premorbidity was not higher than the non-bereaved parents' prevalence adds important information for further intervention studies. The knowledge is also valuable for contradicting the prejudiced assumption that suicide primarily occurs in especially vulnerable families.

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Contributors PO, BR, UN and GS designed the study. PO performed the data collection supervised by GS and UN. TN and PO analysed the data. PO wrote the first draft of the report. UN, GS, BR and TN commented on the report, which PO and UN revised. All authors contributed to the discussion and have seen the final version of the paper. PO (guarantor) and all the coauthors had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

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Competing interests PO and UN have received research grants from The Swedish Council for Working Life Social Research (FAS), ALF Grants, County Council of Stockholm and Swedish Lundbeck foundation for the submitted work; BR has been paid for developing and delivering educational presentations for Lundbeck and AstraZeneca.

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Viewing the Body after Bereavement due to Suicide. A Population-Based Survey in Sweden.

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ABSTRACT

Background

Research on the assumed, positive and negative, psychological effects of viewing the body after a suicide loss is sparse and findings incongruent. We hypothesized that suicide-bereaved parents that viewed their child´s body in a formal setting seldom regretted the experience, and that viewing the body was associated with lower levels of psychological morbidity two to five years after the loss.

Methods and findings

We identified 915 suicide-bereaved parents by linkage of nationwide population-based registries and collected data by a questionnaire. The outcome measures included the Patient Health Questionnaire [PHQ-9]. In total, 666 (73%) parents participated. Of the 460 parents (69%) that viewed the body, 96% answered that they did not regret the experience. The viewing was associated with a higher risk of reliving the child's death through nightmares (RR 1.61, 95% CI 1.13 to 2.32) and intrusive memories (RR 1.20, 95% CI 1.04 to 1.38), but not with anxiety (RR 1.02, 95% CI 0.74 to 1.40) and depression (RR 1.25, 95% CI 0.85 to 1.83). One limitation of our study is that we lack data on the informants' personality and coping strategies.

Conclusions

In this Swedish population-based survey of suicide-bereaved parents, we found that viewing the body in a formal setting was associated with low regrets, although no positive and some negative effects on the psychological outcomes were found. Our findings suggest that bereaved parents are capable of deciding if they want to view the body or not and to handle the psychological consequences of doing so. Officials may assist by giving careful information about the child's appearance and other details concerning the viewing, thus facilitating mental preparation for the bereaved person. This is the first large-scale study on the effects of viewing the body after a suicide and additional studies are needed before clinical recommendations can be made.

INTRODUCTION

Viewing the body after a sudden death is often said to be helpful for bereaved family members [1]-[2]. Chapple and Ziebland [1] found that relatives, bereaved through suicide or other traumatic deaths, who had chosen to view the body seldom regretted doing so. They also found that the relatives often had numerous reasons for viewing the body and mentioned the need for checking the identity, to care for the dead one and to say goodbye. These findings were based on 80 in-depth interviews conducted in Great Britain between 2007 and 2008, four months to nine years after the loss. The benefits of viewing the body after an unexpected death may also be explained by applying grief theories and the notion that facing the dead person facilitates the grief process by bringing reality to the death and by providing an opportunity for closures [1], [3], [4]. There are also relatives who do not want to view the body; some want to remember the person as he or she was when being alive, others want to spare themselves from a fearful sight and unwanted memories [1]. The fear of unwanted memories is also an explanation to why health care professionals sometimes are unwilling to show a disfigured body [5]. Research on the assumed (positive and negative) psychological effects of viewing the body after a suicide loss is however sparse and the findings incongruent.

In this population-based study we used the personal identification numbers and the nationwide high-quality registers to identify a large sample of unselected suicide-bereaved parents. We thereafter used a detailed questionnaire with psychometric scales and study-specific questions to test our hypotheses: parents that viewed their child´s body in a formal setting seldom regretted the experience, and that viewing the body was associated with lower levels of psychological morbidity two to five years after the loss.

METHODS

Ethics Statement

We identified the study population by linkages of registers. In Sweden, the use of register data always needs ethical approval by the regional ethical review boards. Additionally, the register holders make a risk assessment related to The Law on Public Disclosure and Security. We contacted all parents by means of an introduction letter followed by a telephone call. The letter contained information about the study and contact details for the researchers. In the letter we emphasized that participation was voluntary and informed about the possibility to end participation at any time without further explanation. During the telephone call we repeated the information from the letter and asked if the parent wanted to participate and if we could send a questionnaire. The informed oral consent of participation was noted in our database and confirmed by a returned and completed questionnaire. For ethical reasons, we did not obtain a written consent during contact as we did not want the parents to feel pressured to complete participation. The data used in this paper were analyzed anonymously; we could therefore not obtain a written consent afterwards. Our study as well as our contact and consent procedures were approved by the Regional Ethical Review Board in Stockholm, Sweden. Our ethical protocol for data collection and contact is published at: http://dx.doi.org/10.1017/S0033291713001670 [6].

Subjects

We identified all individuals, 15 to 30 years old, who died by suicide (ICD 10: X60-X84) between 2004 and 2007 and also identified their parents by linkage of the nationwide Swedish Cause of Death Register and the Multi-generation Register [7]. To be included in the study, the parent had to be born in one of the Nordic countries, be able to communicate in Swedish and have an identifiable address and telephone number. Furthermore, parents who had lost more than one child were excluded. In total, 915 parents were identified as eligible.

Data collection and measurements

We developed the study design from the routines established by the Division of Clinical Cancer Epidemiology [6], [8]-[10]. Using qualitative methods, we formed study-specific questions on the basis of seventeen in-depth interviews with suicide-bereaved parents [9]. Psychological outcomes were measured by: The two-item Generalized Anxiety Disorder scale (GAD-2) [11], [12] and The nine-item depression scale of the Patient Health Questionnaire (PHQ-9) [13], [14]. To assess the prevalence of nightmares, intrusion and avoidance related to the child's death we used the study specific questions presented in table 4. Furthermore, we used four questions with follow-up questions (presented in table 3) to asses if the parents had viewed the body in a formal setting and if it was during dignified circumstances. Study specific questions, with space for free comments, were used to assess circumstances related to the suicide and the viewing (presented in table 2). All questions, including the psychometric scales, were tested in a preparatory study that included 46 suicide-bereaved persons from our study population [9]. We contacted all eligible parents by an introductory letter followed by a telephone-call to obtain consent to send a questionnaire. We started the data collection in August 2009 and the last questionnaire was returned in December 2010 [9].

Statistical analysis

We used Wilcoxon-Mann-Whitney's test to assess the association between the level of exposure and the levels of psychological outcomes. Using recommended cut-offs [11], [13] we dichotomized the scores derived from the psychometric scales and used log-binomial regression to calculate relative risks. We performed a variable selection among possible confounders, using logistic regression with forward selection in order to identify those variables most strongly related to the outcomes. Since we wanted to maximize the possibility to find other explanatory factors that could potentially disprove the assumed effect of viewing the body, we used a liberal inclusion criterion allowing variables up to the 15% significance level entry. We then formed one final model for each outcome utilizing all variables that had been identified as associated with the outcome and reported the results by adjusted odds ratios. We performed statistical tests at the 5% significance level unless otherwise stated and excluded individuals with missing data in each respective calculation. All statistical analyses were performed with IBM SPSS Statistics software, version 19.0.

RESULTS

Primary outcomes

The questionnaires were returned by 666 of the 915 (73%) suicide-bereaved parents, 460 (69%) of whom stated that they had viewed the body in a formal setting, 202 (30%) that they had not, and four (<1%) did not respond to the questions (Table 1). The question "Do you regret that you viewed your child after the death" was answered by 456 of the 460 parents that had viewed. Ten answered that they had not viewed the body. Of the remaining 446, 430 (96%) answered "No", 9 (2%) "Yes, little", 2 (<1%) "Yes, moderate" and, 5 (1%) "Yes, much" (Data not shown in table). According to the written comments, several of the parents that regretted viewing the child had witnessed a decomposed body. Some of the ones that regretted viewing also wrote that they wished that they had been better prepared for the scene that met them. Regrets were significantly lower among those who had lost a son or daughter to a violent suicide than among those who had lost a son or daughter by poisoning (relative risk 0.19, 95 percent confidence interval 0.07 to 0.49) (Data not shown in table).

The question "Do you wish that you had viewed your child after the death" was answered by 198 of the 202 parents that did not view the body in a formal setting. Thirty-nine answered that they had viewed the child. Of the remaining 159, 99 (62%) answered "No", 25 (16%) "Yes, little", 11 (7%) "Yes, moderate" and, 24 (15%) "Yes, much" (Data not shown in table). According to the written comments several of the ones that did not view the body had been advised by the officials not to do so, since the body was severely damaged or had started to decompose.

Five of the 460 parents that had viewed the body in a formal setting did not answer any of the questions regarding whether they perceived that the viewing was performed in a dignified way. Of the remaining 455, 19 (4%) answered “No”, 21 (5%) “Yes, little”, 63 (14%) “Yes, moderate” and, 352 (77%) “Yes, much” on at least one question regarding if the viewing was performed during dignified circumstances (Table 2).

Secondary outcomes

Viewing the child in a formal setting was associated with a statistically significantly higher risk of having relived the child’s death through nightmares (relative risk 1.61, 95 percent confidence interval 1.13 to 2.32) and intrusive memories (relative risk 1.20, 95 percent confidence interval 1.04 to 1.38) at least occasionally during the preceding month. No statistically significant difference was found concerning anxiety (GAD-2, score ≥ 2) (relative risk 1.02, 95 percent confidence interval 0.74 to 1.40) and depression (PHQ-9, score ≥ 10) (relative risk 1.25, 95 percent confidence interval 0.85 to 1.83) (Table 4).

DISCUSSION

This is the first large population-based study on psychological reactions to viewing the body after a suicide. In this two to five year follow up of 666 parents that had lost a son or daughter to suicide, we found that by and large everyone that had viewed their deceased child in a formal setting did not regret the viewing. Of equal importance, more than half of those who did not view the body did not wish that they had. In contrast to what we hypothesized, we found that those parents who had viewed the body in a formal setting had a statistically significantly higher risk of reliving the child’s death through nightmares (relative risk 1.61, 95 percent confidence interval 1.13 to 2.32) and intrusive memories (relative risk 1.20, 95 percent confidence interval 1.04 to 1.38). We found no statistically significant difference concerning anxiety (relative risk 1.02, 95 percent confidence interval 0.74 to 1.40) and depression (relative risk 1.25, 95 percent confidence interval 0.85 to 1.83) (Table 4).

Our findings that most parents who viewed the body do not regret doing so correspond with findings from previous studies [1], [2]. As in Chapple and Ziebland’s study [1], only a few persons stated that they regretted viewing of the body. In our study regrets were often followed by a comment that expressed shock over how their loved ones had changed. Providing information on what to expect has been stressed as an important element in reducing distress and regrets due to viewing the body after a traumatic death [1], [2], [15]. Interestingly, in our study, regrets were most often associated with death by poisoning rather than a violent method of suicide. The written comments also showed that the regrets mainly concerned witnessing a decomposed body rather than a body that was disfigured by the suicide. Possible explanations might be that after a violent death the relatives are better informed on what to expect and the body is more often shielded. The violently bereaved parents might also expect the worst. Our findings suggest it is always important to inform the parents about the body’s appearance and about options for the viewing, whatever the mode of death. Health care personnel are often encouraged to carefully prepare the environment and the body before the viewing [2], [16], [17]. However, after an as yet unverified suicide, cleaning the body may be delayed due to an ongoing police investigation. In our study, nearly everyone felt that the viewing took place during dignified circumstances, which suggests that the routines for viewing are efficient in Sweden and that complicating factors like an unprepared or damaged body might be accepted if the bereaved are carefully informed and supported during the viewing.

Our finding that the majority of the persons that did not view the body did not wish they had, agrees with previous findings [1], [2]. There are also some who did not view who afterwards wished that they had. Chapple and Ziebland [1] showed that some respondents changed their mind regarding what they thought was best for them and that some, afterwards, were ambivalent about whether their decision was the best one. One explanation might be that these individuals may hold a belief that viewing is necessary for a healthy recovery, a view suggested by some respondents in our study as well as in the grief literature. Dublin and Sarnoff's review [2] from 1986 concludes that bereaved persons should be offered the opportunity to view the body but also stress that those who are reluctant or unwilling to do so must be supported by being told that their decision was the right one for them.

Our hypothesis that those who viewed the body in a formal setting would have lower levels of psychological morbidity than those who did not view was not supported by our findings. In contrast, viewing was associated with a higher risk of reliving the child's death through nightmares and intrusive memories although no differences could be found regarding anxiety, depression or avoidance two to five years after the death (Table 4). Research on the psychological effects of viewing the body after a suicide loss is sparse. We found two studies that explored how confronting the body (at the scene of the death and at a formal setting) affected the level of grief difficulties among suicide-bereaved relatives [18], [19]. In this paper we chose to restrict the discussion to findings concerning viewing in the formal setting. Callahan's study [18] included 210 persons who had lost a family member or a close friend to suicide. The bereaved were all participants in suicide support groups and data were collected in Michigan (1989 to 1993) and Chicago (1995 to 1996) with the average elapsed time since loss four years. Callahan hypothesized that "Not seeing the deceased's body at the funeral or memorial service" was associated with higher levels of grief as measured by the Grief Experience Questionnaire but found no impact on the overall level of grief. Feigelman and co-workers [19] studied a sub-group of 462 parents who had lost their son or daughter to suicide during a time span of less than a year to more than 10 years. An abbreviated version of the Grief Experience Questionnaire was used for the outcome measures and the parents were identified by suicide support groups in the USA. Figelman and co-workers hypothesized that the suicide-bereaved who had viewed the body prior to the burial or cremation (n=189) would experience higher levels of grief difficulties than those who had not viewed the body prior to the burial or cremation (n=96) (the parents that had seen the body at the site of the death were not included in any of the groups) and found that those who had not viewed had a lower level of grief difficulties than those who had viewed. Our findings on the psychological effect of viewing the body in a formal setting are in line with Callahan and Figelmans's findings, thus challenging the notion that viewing the body is necessary for a healthy grief recovery.

Our study has several strengths; one is the large sample of suicide-bereaved parents, all identified through nationwide high-quality registers. Another is the high participation rate among both men and women. Our study also has limitations. The opportunity and decision to view or not to view the body are influenced by numerous factors, some of them known, others not. We have no quantitative data on whether the parents wanted and/or had the choice to view the body at the time of death. However, the written comments to the questions suggest similar to previous studies that the decision often was influenced by other persons and circumstances surrounding the body [1], [5]. We also lack information about possible confounders' related to different personality and coping strategies since existing inventories were considered too immense and the study-specific questions from the preparatory study imprecise [9]. Although most of our questions concern how the parents feel today some answers may be affected by recall-induced problems.

We addressed the threats to validity by employing epidemiological methods as transferred to this field by the hierarchical step-model for study design, analysis and data interpretation [20]. Efforts to reduce the problem of misclassification included a thorough preparatory study, developing and testing the questions and the psychometric scales in close collaboration with parents from the study-population [9]. Our main outcomes were measured by psychometric as well as study-specific questions and we have no reason to believe that the ones who viewed the body and the ones that did not view differ systematically in their response to these questions [21]. It is likely that the fundamental manifestations of grief are universal but still, generalisation to other populations may be compromised by culture-specific issues.

In summary, in this Swedish population-based study, we found that by and large everyone that had viewed their deceased child in a formal setting did not regret doing so. We also found that the majority of the parents that did not view their deceased child did not wish that they had. We found no support for the position that viewing the body in a formal setting had a positive effect on the psychological outcomes, two to five years after the loss. Although no recommendations can be made, our findings suggest that the Swedish routines for viewing the body in a formal setting work satisfyingly. This routine specifies that it is the bereaved person that should make the informed consent to view or not to view the body and that the officials may support the parents in their decision by carefully informing about the child's appearance and how the viewing may be altered, for example, by shielding parts of the body. For parents that seek advice, the officials may also tell them that previous research suggests that most parents that want to see their child do not regret doing so and that viewing often is perceived as helpful although not necessary for a healthy recovery.

Footnotes

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Contributorship statement: PO, BR, UN and GS designed the study. PO performed the data collection supervised by GS and UN. TN and PO analysed the data. PO wrote the first draft of the report. UN, GS, BR and TN commented on the report, which PO and UN revised. All authors contributed to the discussion and have seen the final version of the paper. PO (guarantor) and all the co-authors had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

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Table 1. Sociodemographic characteristics of the suicide-bereaved parents

	Suicide-bereaved parents	
	Viewed at formal setting[*]	Did not view at formal setting
Sex – no. (%)		
Fathers	185/282 (65.6)	97/282 (34.4)
Mothers	275/380 (72.4)	105/380 (27.6)
Age – yr		
Fathers, Median (Interquartile range)	58 (54 to 62)	58 (53 to 62)
Mothers, Median (Interquartile range)	55 (51 to 59)	56 (52 to 60)
Year of child's death – no. (%)		
2004	111/162 (68.5)	51/162 (31.5)
2005	114/171 (66.7)	57/171 (33.3)
2006	123/168 (73.2)	45/168 (26.8)
2007	112/161 (69.6)	49/161 (30.4)
Age deceased child – yr Median (Interquartile range)	23 (20 to 26)	24 (20 to 28)
Sex deceased child – no. (%)		
Male	319/458 (69.7)	139/458 (30.3)
Female	141/204 (69.1)	63/204 (30.9)
Children – no. (%)		
No remaining children	27/47 (57.4)	20/47 (42.6)
Remaining children	433/615 (70.4)	182/615 (29.6)
Biological child – no. (%)		
Non biological child	21/31 (67.7)	10/31 (32.3)
Biological child	439/631 (69.6)	192/631 (30.4)
Family constellation at time of study – no. (%)		
Living with a partner	345/475 (72.6)	130/475 (27.4)
Has a partner but lives alone	27/44 (61.4)	17/44 (38.6)
Single	78/121 (64.5)	43/121 (35.5)
Widow, widower	8/18 (44.4)	10/18 (55.6)
Residence area – no. (%)		
Rural	111/161 (69.0)	50/161 (31.0)
Village (population less than 10,000)	111/153 (72.5)	42/153 (27.5)
Small town (population less than 50,000)	87/127 (68.5)	40/127 (31.5)
Town (population less than 200,000)	77/117 (65.8)	40/117 (34.2)
Larger town (population more than 200,000)	71/97 (73.2)	26/97 (26.8)
Country of birth – no. (%)		
Born in Sweden	437/625 (70.0)	188/625 (30.0)
Born in other Nordic country	22/36 (61.1)	14/36 (38.9)
Level of education – no. (%)		
Less than elementary school	1/5 (20.0)	4/5 (80.0)
Elementary school	105/141 (74.5)	36/141 (25.5)
Junior college	179/270 (66.3)	91/270 (33.7)
College or university (< 3 years)	57/82 (69.5)	25/82 (30.5)
College or university (≥ 3 years)	116/159 (73.0)	43/159 (27.0)
Source of income – no. (%)		
Employed or self-employed	350/496 (70.6)	146/496 (29.4)
Old-age pension	36/59 (61.0)	23/59 (39.0)
Disability pension	44/61 (72.1)	17/61 (27.9)
Unemployment fund	19/25 (76.0)	6/25 (24.0)
Other	9/16 (56.2)	7/16 (43.8)
Religion – no. (%)		
Do not believe in God	245/354 (69.2)	109/354 (30.8)
Believes in God	200/286 (69.9)	86/286 (30.1)

[*] Parents that stated that they viewed their dead child in a formal setting. We asked if they viewed in the body at "The emergency department or ward", "Hospital church", "Department of forensic medicine", and "Funeral parlour". Viewing also includes viewing the contour of the body or part of the body.

Table 2. Circumstances related to the suicide

	Suicide-bereaved parents	
	Viewed body no./total no. (%)	Did not view no./total no. (%)
How did your child commit suicide		
Poisoning[*]	64/101 (63.4)	37/101 (36.6)
Hanging, strangulation, suffocation	266/345 (77.1)	79/345 (22.9)
Drowning	3/8 (37.5)	5/8 (62.5)
In front of moving vehicles	37/81 (45.7)	44/81 (54.3)
Jumping from a height	36/46 (78.3)	10/46 (21.7)
By firearm discharge	29/45 (64.4)	16/45 (35.6)
Other way	16/24 (66.6)	8/24 (33.3)
How did you know that your child was deceased		
Found dead child	86/109 (78.9)	23/109 (21.1)
Saw dead child at site but not as first person	23/32 (71.9)	9/32 (28.1)
Notified in person	207/297 (69.7)	90/297 (30.3)
Notified by telephone	108/179 (60.3)	71/179 (39.7)
Other way[†]	34/42 (80.0)	8/42 (20.0)
Did you receive the death notice from a professional person		
No	201/292 (68.8)	91/292 (31.2)
Yes	251/358 (70.1)	107/358 (29.9)
If yes, did the person come to your home		
No	95/139 (68.3)	44/139 (31.7)
Yes	186/268 (69.4)	82/268 (30.6)
If yes, did the person stay as long as you wanted		
No, too short	32/45 (71.1)	13/45 (28.9)
No, too long	4/5 (80.0)	1/5 (20.0)
Yes	176/257 (68.5)	81/257 (31.5)
Where you informed that your child died by suicide at the time of the death notice		
No	52/68 (76.5)	16/68 (23.5)
Yes	339/508 (66.7)	169/508 (33.3)
Was the death notice given in a dignified way		
No	61/79 (77.2)	18/79 (22.8)
Yes, a little	51/75 (68.0)	24/75 (32.0)
Yes, moderate	78/112 (69.6)	34/112 (30.4)
Yes, much	144/225 (64.0)	81/225 (36.0)
Where you prepared that your child might have committed suicide, when you received the death notice		
No	261/361 (72.3)	100/361 (27.7)
Yes, a little	64/88 (72.7)	24/88 (27.3)
Yes, moderate	22/33 (66.7)	11/33 (33.3)
Yes, much	83/138 (60.1)	55/138 (39.9)
How long time proceeded between your child’s death and you being notified about his or her death		
0 – 3 hours	151/208 (72.6)	57/208 (27.4)
4 – 6 hours	93/131 (71.0)	38/131 (29.0)
7 – 12 hours	97/137 (70.8)	40/137 (29.2)
13 – 23 hours	56/79 (70.9)	23/79 (29.1)
1 – 3 days	47/71 (66.2)	24/71 (33.8)
4 – 6 days	7/19 (36.8)	12/16 (63.2)
1 – 3 weeks	3/7 (42.9)	4/7 (57.1)
One month or more	0/3 (0.0)	3/3 (100.0)

[*] Poisoning for example by medication, chemicals or some kind of gas”. [†] Of the 40 parents that stated “Other way” 17 wrote that they were present at the time of death; 11 at the hospital and 6 had witnessed the suicide, 23 parents wrote that they received the death notice from someone else and two did not comment on the question.

Table 3. Suicide-bereaved parents experience of viewing the body at formal settings

Did you view your child at:	**No**	**Yes**	*a little*	*moderate*	*much*	**Missing**
	no./tot no. (%)					
The Hospital (ER, Ward)	517 (77.6)	140 (21.0)				9 (1.4)
If yes, was it during dignified circumstances	8 (5.7)		11 (7.9)	22 (15.7)	97 (69.3)	2 (1.4)
The Hospital church	431 (64.7)	227 (34.1)				8 (1.2)
If yes, was it during dignified circumstances	7 (3.1)		9 (4.0)	30 (13.2)	178 (78.4)	3 (1.3)
Forensic medicine	555 (83.3)	98 (14.7)				13 (2.0)
If yes, was it during dignified circumstances	2 (2.0)		4 (4.1)	15 (15.3)	73 (74.5)	4 (4.1)
The Funeral parlour	448 (67.3)	209 (31.4)				9 (1.4)
If yes, was it during dignified circumstances	5 (2.4)		3 (1.4)	17 (8.1)	176 (84.2)	8 (3.8)
Any of the above*	202 (30.3)	460 (69.1)				4 (0.6)
If yes, was it during dignified circumstances†	19 (4.1)		21 (4.6)	63 (13.7)	352 (76.5)	5 (1.1)

[*] “Emergency department or ward”, “Hospital church, “Department of forensic medicine”, and “Funeral parlour”. Viewing also includes viewing the contour of the body or part of the body. [†] The most unfavourable value ranging from “No”; “Yes, a little”; “Yes, moderate”; “Yes, much” at any of the formal settings.

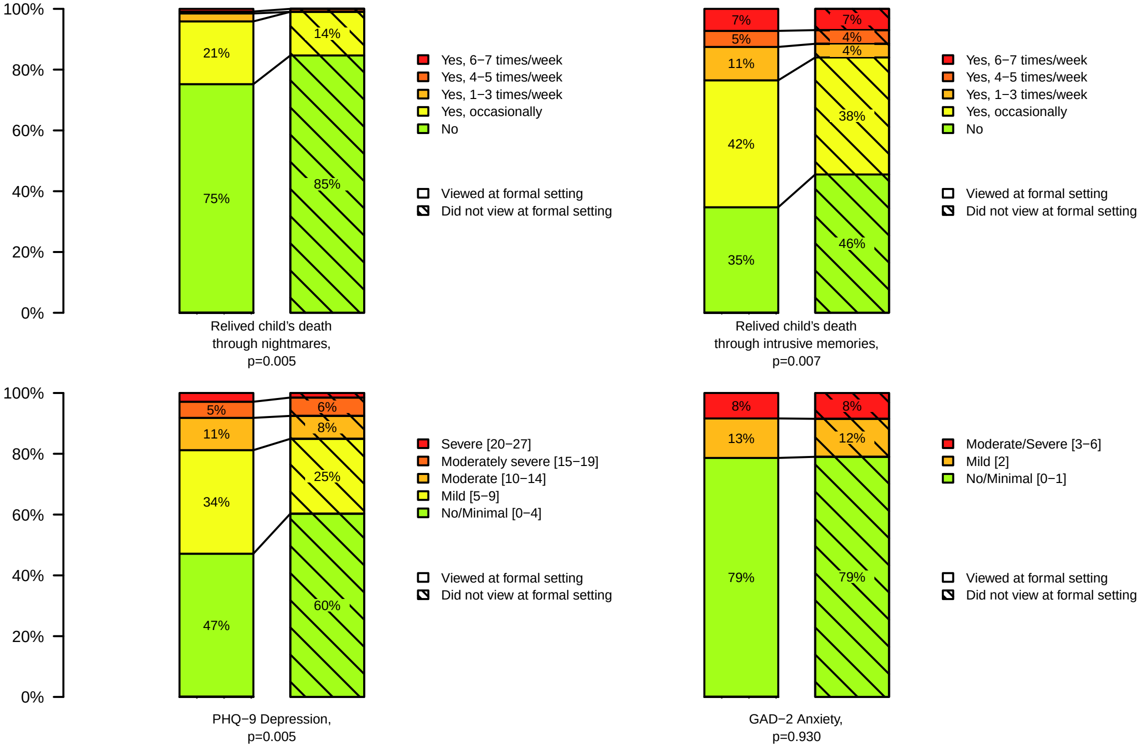
Table 4. Psychological outcomes among the parents that viewed and did not view the body

	Suicide-bereaved parents		
Variables no. /total no. (%)	Viewed in a formal setting[*]	Did not view in a formal setting	Trend test P value
Relived child's death through nightmares the last month[†]	114/460 (24.8)	31/202 (15.3)	
Relative Risk (95% CI)	1.61 (1.13 to 2.32)	1.0 (reference)	0.005
Unadjusted odds ratios	1.82 (1.17 to 2.81)	1.0 (reference)	
Adjusted odds ratios[‡][§][**]	1.85 (1.16 to 2.95)	1.0 (reference)	
Relived child's death through intrusive memories the last month[†]	297/455 (65.3)	109/200 (54.5)	
Relative Risk (95% CI)	1.20 (1.04 to 1.38)	1.0 (reference)	0.007
Unadjusted odds ratios	1.57 (1.12 to 2.20)	1.0 (reference)	
Adjusted odds ratios[‡][§][††]	1.50 (1.04 to 2.16)	1.0 (reference)	
Avoided thinking about things that reminds about child's death the last month[†]	156/458 (34.1)	57/200 (28.5)	
Relative Risk (95% CI)	1.20 (0.93 to 1.54)	1.0 (reference)	0.276
Unadjusted odds ratios	1.30 (0.90 to 1.86)	1.0 (reference)	
Adjusted odds ratios[‡][§][‡‡]	1.28 (0.86 to 1.91)	1.0 (reference)	
Avoided things that reminds about child's death the last month e.g. places and things[†]	118/457 (25.8)	52/197 (26.4)	
Relative Risk (95% CI)	0.98 (0.74 to 1.30)	1.0 (reference)	0.927
Unadjusted odds ratios	0.97 (0.66 to 1.42)	1.0 (reference)	
Adjusted odds ratios[‡][§][§§]	1.01 (0.66 to 1.54)	1.0 (reference)	
Depression (PHQ-9 score ≥ 10)[***]	85/452 (18.8)	30/199 (15.1)	
Relative Risk (95% CI)	1.25 (0.85 to 1·83)	1.0 (reference)	0.005
Unadjusted odds ratios	1.30 (0.83 to 2·06)	1.0 (reference)	
Adjusted odds ratios[‡][†††][‡‡‡]	1.27 (0.76 to 2.12)	1.0 (reference)	
Anxiety (GAD-2 score ≥ 2)[§§§]	97/454 (21.4)	42/200 (21.0)	
Relative Risk (95% CI)	1.02 (0.74 to 1.40)	1.0 (reference)	0.893
Unadjusted odds ratios	1.02 (0.68 to 1.54)	1.0 (reference)	
Adjusted odds ratios[‡][†††][****]	0.89 (0.56 to 1.40)	1.0 (reference)	

[*] Parents that stated that they viewed their dead child in a formal setting. We asked if they viewed in the body at "The emergency department or ward", "Hospital church", "Department of forensic medicine", and "Funeral parlour". [†] "No"," Yes, occasionally", "Yes, 1–3 days a week", "Yes, 4–5 days a week", "Yes, 6–7 days a week". Dichotomized into "No" and "Yes". [‡] OR adjusted for multiple variables selected by logistic regression forward selection. Variables that met the 0.15 significant level were included in the models. [§] Variables in the selection: sex, age, residence, civil status, income, education. physical activity, social activity, violent suicide, found dead child, death notice, contact, AUDIT, PHQ, GAD, sleeping pill, anxiolytics, and antidepressants. [**] Selected variables: GAD, sleeping pill, education, and sex [††] Selected variables: GAD, sex, sleeping pill, physical activity, and age. [‡‡] Selected variables: PHQ, social activity, sex, GAD, and age. [§§] Selected variables: PHQ, sex, social activity, GAD, physical activity, income and, violent suicide. [***] PHQ-9 score 0–27. Answering categories: "Not at all", "1–3 days a week","4–5 days a week", and "6–7 days a week". [†††] Variables in the selection: sex, age, residence, civil status, income, education. physical activity, social activity, violent suicide, found dead child, death notice, contact, and AUDIT. [‡‡‡] Selected variables: Income, sex, AUDIT, social activity, physical activity, age, and civil status. [§§§] GAD-2 scores 0–6. Answering categories: "Not at all", "1–3 days a week","4–5 days a week", and "6–7 days a week". [****] Selected variables: Income, sex, physical activity, social activity, AUDIT, and age.

No/total no (%)	**Regret formal viewing[*]**	**Nightmares**	**Intrusive memories**	**Avoiding thoughts**	**Avoiding places**	**Depression (PHQ-9)**	**Anxiety (GAD-2)**
Saw[*†] the dead child							
	n=460	n=666	n=666	n=666	n=666	n=666	n=666
No	-	29/171 (17.0)	96/170 (56.5)	50/170 (29.4)	44/167 (26.3)	26/169 (15.4)	35/170 (20.6)
Yes	16/446 (3.6)	117/493 (23.7)	312/487 (64.1)	163/490 (33.3)	127/489 (26.0)	89/484 (18.4)	104/486 (21.4)
RR (CI 95%)	-	0.71 (0.49 to 1.03)	0.88 (0.76 to 1.02)	0.88 (0.68 to 1.15)	1.01 (0.76 to 1.36)	0.84 (0.56 to 1.25)	0.96 (0.68 to 1.35)
Trend test P value	-	**0.048**	**0.037**	0.485	0.960	**0.009**	0.823
Discovered/saw body at the site of death	n=460	n=666	n=666	n=666	n=666	n=666	n=666
Yes	5/111 (4.5)	31/147 (21.1)	88/145 (60.7)	46/145 (31.7)	35/144 (24.3)	24/143 (16.8)	29/145 (20.0)
No	11/333 (3.3)	114/512 (22.3)	317/507 (62.5)	167/510 (32.7)	136/507 (26.8)	90/505 (17.8)	109/506 (21.5)
RR (CI 95%)	1.36 (0.48 to 3.84)	0.95 (0.67 to 1.35)	0.97 (0.84 to 1.13)	0.97 (0.74 to 1.27)	0.91 (0.66 to 1.25)	0.94 (0.62 to 1.42)	0.93 (0.64 to 1.34)
Trend test P value	0.537	0.833	0.613	0.863	0.627	0.963	0.637
Viewed the body in a formal setting[*]	n=460	n=666	n=666	n=666	n=666	n=666	n=666
No	Not applicable	31/202 (15.3)	109/200 (54.5)	57/200 (28.5)	52/197 (26.4)	30/199 (15.1)	42/200 (21.0)
Yes	16/446 (3.6)	114/460 (24.8)	297/455 (65.3)	156/458 (34.1)	118/457 (25.8)	85/452 (18.8)	97/454 (21.4)
RR (CI 95%)	Not applicable	**0.62 (0.43 to 0.89)**	**0.84 (0.72 to 0.96)**	0.84 (0.65 to 1.08)	1.02 (0.77 to 1.35)	0.80 (0.55 to 1.17)	0.98 (0.71 to 1.36)
Trend test P value		**0.005**	**0.007**	0.276	0.927	**0.005**	0.893
Perceived formal viewing worthy	n=460	n=460	n=460	n=460	n=460	n=460	n=460
No	5/18 (27.8)	7/19 (36.8)	14/18 (77.8)	10/19 (52.6)	10/19 (52.6)	3/18 (16.7)	1/18 (5.6)
Yes	11/423 (2.6)	106/436 (24.3)	279/432 (64.6)	144/434 (33.2)	106/433 (24.5)	81/429 (18.9)	96/431 (22.3)
RR (CI 95%)	**10.68 (4.15 to 27.51)**	1.52 (0.82 to 2.79)	1.20 (0.93 to 1.56)	**1.59 (1.02 to 2.48)**	**2.15 (1.36 to 3.40)**	0.88 (0.31 to 2.53)	0.25 (0.04 to 1.69)
Trend test P value	**<0.001**	0.284	0.073	0.056	**0.005**	0.236	0.114
Circumstances related to the suicide	n=460	n=666	n=666	n=666	n=666	n=666	n=666
Violent suicide[‡]	8/375 (2.1)	120/549 (21.9)	340/543 (62.6)	175/545 (32.1)	146/541 (27.0)	92/540 (17.0)	111/541 (20.5)
Poisoning[§]	7/61 (11.5)	21/101 (20.8)	59/100 (59.0)	36/101 (35.6)	21/101 (20.8)	22/99 (22.2)	25/101 (24.8)
RR (CI 95%)	**0.19 (0.07 to 0.49)**	1.05 (0.70 to 1.59)	1.06 (0.89 to 1.27)	0.90 (0.68 to 1.20)	1.30 (0.87 to 1.95)	0.77 (0.51 to 1.16)	0.83 (0.57 to 1.21)
Trend test P value	**<0.001**	0.895	0.625	0.649	0.150	0.856	0.339
Death notice ≥ 24h	3/55 (5.5)	19/100 (19.0)	54/100 (54.0)	26/100 (28.0)	24/99 (24.2)	17/98 (17.3)	21/99 (21.2)
Death notice < 24h	13/385 (3.4)	125/557 (22.4)	347/550 (63.1)	182/553 (32.9)	144/550 (26.2)	97/548 (17.7)	116/550 (21.1)
RR (CI 95%)	1.61(0.48 to 5.49)	0.85 (0.55 to 1.31)	0.87 (0.71 to 1.04)	0.85 (0.61 to 1.19)	0.93 (0.64 to 1.35)	0.98 (0.61 to 1.57)	1.01 (0.67 to 1.52)
Trend test P value	0.445	0.456	0.216	0.334	0591	0.607	0.943

[*] Parents stated that viewed their dead child in a formal setting: “Emergency department or ward”, “Hospital church”, “Department of forensic medicine”, and “Funeral home”. [†]Parents that found their dead child, were present at the time of death and, witnessed the suicide. [‡] Parents that stated that their child committed suicide by “Hanging, strangulation, suffocation”, “Drowning”, “By moving vehicles, “Jumping from a height”, “By firearm discharge”, “Cutting or stabbing” and, “By fire.[§] Formulated in the questionnaire as “Poisoning for example by medication, chemicals or some kind of gas”.


100%
80%
60%
40%
20%
0%
21%
75%
14%
85%
Relived child's death
through nightmares,
p=0.005
Yes, 6−7 times/week
Yes, 4−5 times/week
Yes, 1−3 times/week
Yes, occasionally
No
Viewed at formal setting
Did not view at formal setting
7%
5%
11%
42%
35%
7%
4%
4%
38%
46%
Relived child's death
through intrusive memories,
p=0.007
Yes, 6−7 times/week
Yes, 4−5 times/week
Yes, 1−3 times/week
Yes, occasionally
No
Viewed at formal setting
Did not view at formal setting
100%
80%
60%
40%
20%
0%
5%
11%
34%
47%
6%
8%
25%
60%
PHQ−9 Depression,
p=0.005
Severe [20−27]
Moderately severe [15−19]
Moderate [10−14]
Mild [5−9]
No/Minimal [0−4]
Viewed at formal setting
Did not view at formal setting
8%
13%
79%
8%
12%
79%
GAD−2 Anxiety,
p=0.930
Moderate/Severe [3−6]
Mild [2]
No/Minimal [0−1]
Viewed at formal setting
Did not view at formal setting