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SUICIDE IN THE FAMILY: TOWARDS IMPROVED CARE OF BEREAVED PARENTS AND SIBLINGS

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SUICIDE IN THE FAMILY: TOWARDS IMPROVED CARE OF BEREAVED PARENTS AND SIBLINGS

THESIS FOR DOCTORAL DEGREE (Ph.D.)

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To those who left and to all who have been left behind. To those who want to comprehend and those who want to help.

ABSTRACT

Background

Losing a child to suicide is an overwhelming experience, which increases the risk for negative health outcomes in the bereaved parents and siblings, such as long-term psychiatric morbidity and increased risk of premature mortality, including suicide. Despite their needs and the increased risk for bereavement related difficulties, there is limited evidence coming from population-based studies for the efficacious care of the suicide-bereaved. The main aim of our studies is to contribute with knowledge in order to improve the professional care of suicide-bereaved parents and siblings by exploring some areas of interest that can be seen as first steps towards this aim.

Methods

We refined our working hypotheses, created a study-specific questionnaire, validated and tested it, including the data collection procedures (**study I**). Also, we interviewed 18 suicide-bereaved siblings and qualitatively analyzed the data concerning their perception of health services (**study II**). Then, using our study-specific questionnaire, we investigated the prevalence and variables associated with lack of trust in the healthcare system in a population of 666 suicide-bereaved parents and 326 non-bereaved-parents (**study III**), and we also investigated the psychological impact of confronting the body of the deceased child at the site of death in the suicide-bereaved parents (**study IV**).

Results

Of the 46 suicide-bereaved parents that answered the questionnaire in our preliminary study, 45 asserted that they found the survey valuable, 24 that they had been positively affected by answering the questionnaire, and 3 that they had been negatively affected. A majority stated that they were grateful for the opportunity to tell about their experience surrounding their child's death (**study I**). We also found that most suicide-bereaved siblings wanted professional help but not all of them sought it due to lack of trust in the helpfulness of health services or because they experienced overwhelming grief. A minority did not feel the need of professional help. Moreover, the deceased sibling's experience with health services became a point of reference that influenced the bereaved siblings' perception of the helpfulness of health services (**study II**). Furthermore, we found that lack of trust in the healthcare system was more prevalent in the suicide-bereaved parents (47%) than in the non-bereaved parents (18%), resulting in a Relative Risk (RR) of 2.5 (95% CI 2.0 – 3.3). Considering only the bereaved parents, the variables associated to lack of trust in the healthcare system were having high scores of depression, as measured by the Patient Health Questionnaire (PHQ-9), living in big cities (>200,000 inhabitants) and being single (**study III**). In **study IV,** we found that confronting the body of the dead child was not associated with a statistically significant higher risk of reliving the child's death through nightmares (RR 0.95, 95% CI 0.67 – 1.35),

intrusive memories (RR 0.97, 95% CI 0.84 – 1.12), avoidance of thoughts (RR 0.97, 95% CI 0.74 – 1.27), avoidance of places or things (RR 0.91, 95% CI 0.66 – 1.25), anxiety (RR 0.93, 95% CI 0.64 – 1.34) or depression (RR 0.94, 95% CI 0.63 – 1.42) when comparing parents who confronted the body of their child with parents who did not.

Conclusions

Suicide-bereaved parents may participate in research studies including sensitive questions, as long as the research process follows robust ethical and methodological procedures (**study I**). The suicide-bereaved siblings' perception that the care provided to their deceased sibling was deficient, may produce negative attitudes towards health services and also low expectations regarding the helpfulness of health services (**study II**). The prevalence of lack of trust in the healthcare system was larger in the suicide-bereaved parents than in the non-bereaved parents. Their lack of trust was found to be associated with having high scores of depression, living in big cities and being single (**study III**). Regarding the psychological impact of confronting the body of the child at the scene of death, we found no significant statistical differences between parents who confronted the body of the deceased child and parents who did not (**study IV**).

LIST OF SCIENTIFIC PAPERS

I. P. Omerov, G. Steineck, B. Runeson, A. Christensson, U. Kreicbergs, **R. Pettersén**, B. Rubenson, J. Skoog, I. Rådestad, U. Nyberg. Preparatory studies to a population-based survey of suicide-bereaved parents in Sweden. Crisis 2013; 34:200-10

II. **R. Pettersén,** P. Omerov, G. Steineck, A. Dyregrov, D. Titelman, K. Dyregrov, U. Nyberg. Suicide-bereaved siblings' perception of health services. Accepted for publication in: Death Studies 2015

III. **R. Pettersén,** P. Omerov, G. Steineck, D. Titelman, A. Dyregrov, T. Nyberg, U. Nyberg. Lack of trust in the healthcare system after losing a child to suicide: a nationwide population survey. Accepted for publication in: Crisis, 2015.

IV. P. Omerov, **R. Pettersén,** G. Steineck, D. Titelman, A. Dyregrov, T. Nyberg, U. Nyberg. Confronting the body at the site of the suicide: population-based survey in Sweden. Submitted

CONTENTS

LIST OF ABBREVIATIONS

CG	Complicated Grief
DSM	Diagnostic and Statistical Manual of Mental Disorders
GAD	Generalized Anxiety Disorder
ICD	International Classification of Causes of Death and Diseases
ICG	Inventory of Complicated Grief
MDD	Major Depressive Disorder
MDE	Major Depressive Episode
NASP	National Centre for Suicide Research and Prevention of Mental Ill-Health
PCBD	Persistent Complex Bereavement Disorder
PD	Panic Disorder
PGG	Prolonged Grief Disorder
PHQ-9	The 9-item depression scale from the Patient Health Questionnaire
PTSD	Posttraumatic Stress Disorder
SPES	Riskförbundet för SuicidPrevention och Efterlevandes Stöd (Swedish Self-help Group for Suicide Survivors)
WHO	World Health Organization

1 INTRODUCTION

When I studied psychology, the last year of the program consisted of an internship. Since I chose Clinical Psychology as my orientation, I was sent to work at a psychiatric unit in a hospital under supervision of a psychiatrist and two psychologists. With time and practice, I gained more and more confidence to perform clinical assessments and provide interventions to patients who presented to the unit with different problems. This confidence was shaken the day I was sent to talk to a couple whose two young boys had ingested poison in a suicide attempt. The youngest had died. I clearly remember their faces, their shock and their pain. I also remember my impotence and confusion. Young children taking their lives and counseling suicide-bereaved parents were topics I was not acquainted with. The lack of clinical guidelines and procedures regarding how to help suicide-bereaved relatives was concerning. The only “help” I saw to be offered to these parents was the concealment of suicide as the cause of death of their child. That year I decided to research suicide in children younger than 12 years old. That was the topic of my thesis of degree. I furthered my studies in suicide research and two years later, I obtained the MSc in Suicide Prevention at the Karolinska Institute. Today, 12 years after that first encounter with suicide-bereaved parents, I finish my PhD journey at the unit of Clinical Cancer Epidemiology at the Karolinska Institute with a doctoral thesis I hope will provide some insights that can be useful towards better care of suicide-bereaved parents and siblings.

1.1 SUICIDE IN THE WORLD

Suicide is a global phenomenon and a serious public health problem. The World Health Organization (WHO) estimates that over 800,000 people die by suicide every year, leaving long-lasting effects in families, among friends and in whole communities. Globally, suicide occurs across the lifespan and in 2012 suicide was the second leading cause of death in the age group between 15-29 years. From all violent deaths in the world, suicide accounts for up to 50% of deaths in men and 71% in women. Concerning age, in almost all countries of the world suicide rates are highest among the elderly (70 years old or older) for both men and women. Regarding gender, in affluent countries the suicide rate in males is higher than in females in a ratio of 3 males per 1 woman (3:1). In low and middle-income countries the ratio is lower, being 1.5 men who commit suicide per each female suicide (1.5:1). Globally, the most common suicide methods used are ingestion of pesticide, hanging and firearms (World Health Organization, 2014).

From the 172 WHO member states, from which data concerning suicide is available, only 60 have good-quality data, which can be used to estimate suicide rates. Poor quality data is not unique to suicide, but it is possible that due to the sensitivity and illegality of suicide in some countries, there is under-registration and misclassification of suicide deaths (World Health Organization, 2014). Other reasons for the underreporting of suicide rates is that the procedures to certificate death by suicide differ between countries and the certification of suicide is made by different entities (i.e. police, physicians, coroners, medical examiners, etc.). Besides, the requirements for a death to be officially reported as a suicide vary between countries. Some require external evidence of intent, like a suicide note, and in other countries it suffices with a verdict judging intent and self-infliction (Hawton & van Heeringen, 2009). These potential biases may influence the comparability of suicide rates between countries. Even in countries with highly reliable data, to diagnose suicide can sometimes be difficult. According to the International Classification of Causes of Death and Diseases (ICD), a physician must distinguish between certain and undetermined suicides when identifying cause of death. "Certain" suicides are those in which there is no doubt that the intention of the deceased was to kill him/herself. "Undetermined" suicides are those in which the physician is unsure if the cause of death was indeed an intentional act or if it was an accident. For example, death by drug overdose sometimes falls into this category (Isacsson, Holmgren, Druid, & Bergman, 1999).

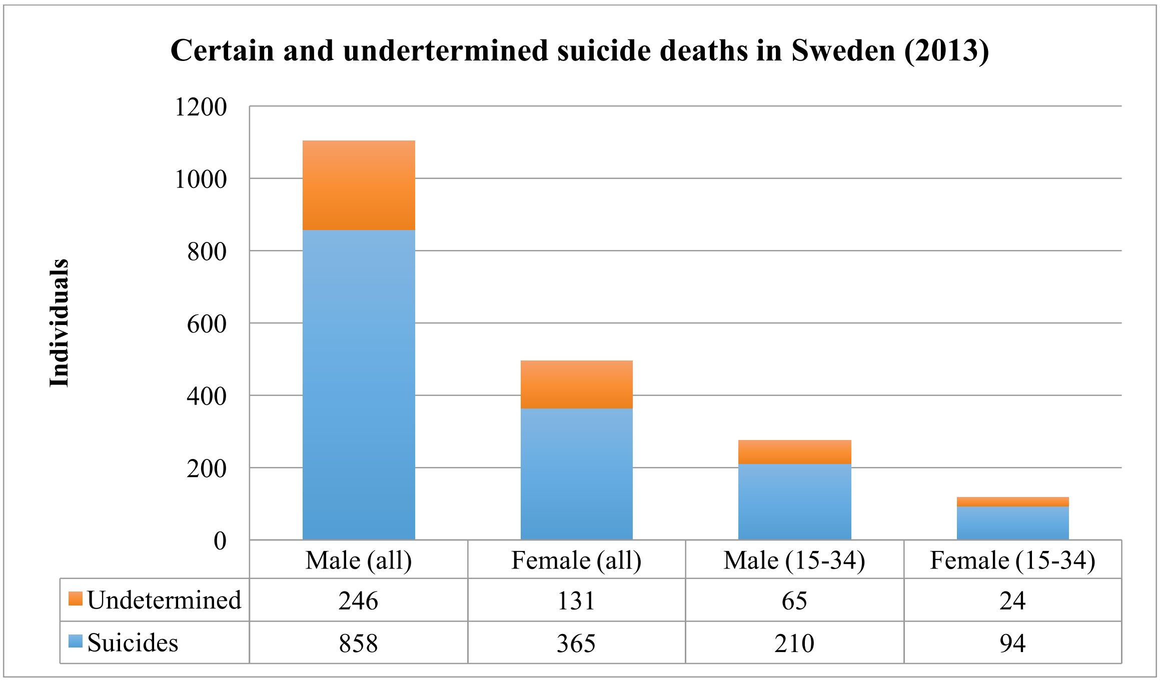
1.2 SUICIDE IN SWEDEN

Suicide rates in Sweden are higher in males than in females. In the year 2013, the male to female ratio was 2.2:1. That is to say that for every woman that took her life, there were 2.2 male suicides. The age group with the highest total numbers of suicides is the one between 45 and 64 years old, both in men and women. The National Centre for Suicide Research and Prevention of Mental Ill-Health (NASP) recommends that, despite the overestimation of suicide rates when undetermined suicides are included, this overestimation is less than the underestimation that would remain if undetermined suicides were not included when reporting national suicide rates (NASP; 2012). According to The National Board of Health and Welfare, 1600 persons died by suicide in Sweden in 2013. These data includes certain and undetermined suicides. From those 1600 persons who died by suicide, 1104 were male and 496 were female. In 2013, suicide rates in Sweden were 16.5 per 100,000 for the total population, 10.3 per 100,000 for females and 22.9 per 100,000 for males. (http://www.socialstyrelsen.se/statistik/statistikdatabas/dodsorsaker). When we investigated suicide-bereaved parents in this research project, we only included those suicide cases registered as certain suicides. The most common suicide methods are hanging in men (36.1%) and poisoning in women (50.3%) (NASP, 2012).

Table 1. Male and female suicide deaths in Sweden in 2013 divided by age groups. Numbers include undetermined and certain suicides. ICD-10 codes: Y20-Y34, Y10-Y19, X70-X84, X60-X69

	15-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	TOTAL
Male	123	152	150	210	187	152	90	40	1104
Female	53	65	65	90	90	72	38	23	496

Figure 1. Certain and undetermined suicide deaths in Sweden in 2013. The National Board of Health and Welfare (Socialstyrelsen).



	Male (all)	Female (all)	Male (15-34)	Female (15-34)
🟧 Undetermined	246	131	65	24
🟦 Suicides	858	365	210	94

2 BACKGROUND

2.1 BEREAVEMENT AND GRIEF

Bereavement refers to the experience of losing a loved one by death and grief is the emotional reaction that follows the death of a loved one which usually includes physical, cognitive and behavioral reactions (Stroebe, Schut & Stroebe, 2007). The intensity, duration and expression of grief vary across individuals and cultures. How an individual responds to bereavement may depend on age and state of development, gender, trauma and loss history, previous depressive disorder, the nature and quality of the relationship with the deceased, type of loss (for example, anticipated, violent or traumatic), preparedness for the loss and other factors (Genevro, Marshall, & Miller, 2004). Despite the immense pain and life changes that a loss brings, most people will recover and only a minority of bereaved persons will develop long-lasting health impairment or will need professional help (Bonanno, 2004). Furthermore, research shows that some bereaved individuals experience positive emotions after the loss (Bonanno & Kaltman, 2001) and other persons, like those who were involved in the care of their sick loved one, may even experience improvement in depressive symptoms after the loved one's death (Bonanno, 2004). However, identifying those individuals who are at risk for more severe mental health problems after a loss, will allow us to channel professional help to those who have the greatest need (M. S. Stroebe, Folkman, Hansson, & Schut, 2006).

2.2 HEALTH OUTCOMES OF BEREAVEMENT

Although some authors point out that the majority of bereaved persons cope well with their loss (Bonanno, 2004), the death of a loved one poses a high risk for adverse health outcomes. A well-researched consequence of bereavement is the increased risk of mortality from various causes, including suicide, in bereaved parents. A Danish nationwide follow-up study based on national registers found that, overall, the death of a child increased the risk of mortality from all causes in mothers, but mainly due to unnatural causes. In the case of the bereaved fathers, they were at increased risk only for unnatural causes and only for a short period of time after their child's death. The authors also observed that the unexpected or unnatural death of a child resulted in higher maternal relative mortality rates in comparison with the expected death of a child (Li, Precht, Mortensen, & Olsen, 2003) . Another nationwide follow-up study concerning mortality after the death of a child was conducted in Sweden. Using data based on the total Swedish population and multiple-linked national registers, the researchers found that the death of a child was associated with an overall increased mortality in parents. This effect was specially pronounced in bereaved mothers that lost a child aged 10-17 at the time of death. Furthermore, four years after their loss, bereaved parents presented the same mortality level than matched non-bereaved parents, but longer follow-up showed that the mortality risk of bereaved parents was higher than in their non-bereaved counterparts (Rostila, Saarela, & Kawachi, 2012).

Literature shows common grief patterns which consist of moderate disruptions in the normal life of individuals after the loss of a significant person. Besides increased risk of mortality due to different causes, other consequences of bereavement can be divided into *affective reactions* such as depression, despair, anxiety, fears, anhedonia, low self esteem, anger, and irritability; cognitive reactions such as difficulties accepting the reality of the loss, memory and concentration difficulties, changed assumptions about the world and other people, and intrusive ruminations; *behavioral reactions* like agitation, fatigue, social withdrawal and over-activity; and *physiological-somatic reactions* like loss of appetite and weight loss, sleep difficulties, reduced energy and somatic complaints like pain (M. Stroebe, Schut, & Stroebe, 2007).

2.2.1 Depression after losing a loved one

In general, most bereaved individuals experience acute suffering after the death of a loved one, which includes the previously mentioned reactions, especially early in their grief. However, this suffering recedes with time for most of the bereaved. Still, there is a relatively small group of individuals for whom symptoms of depression and anxiety can continue overtime and reach clinical levels (Bonanno & Kaltman, 2001).

Prospective studies of bereavement (S. Zisook & Shuchter, 1991) as well as clinical experience, show that there is an overlap between normal grief reactions and some symptoms of depression. A considerable number of bereaved individuals fulfill the diagnostic criteria for Major Depressive Disorder (MDD) – 5 symptoms for at least 2 weeks – and experience clinically significant distress. However, their bereavement-related depression may resolve over time without clinical intervention (Wakefield & First, 2012).

The Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; American Psychiatric Association, 2013) calls for attention to feelings of intense sadness, rumination about the loss, insomnia, poor appetite and weight loss in bereaved people, since these symptoms are also part of the criteria for diagnosis of Major Depression Disorder. The previous version of the DSM excluded bereaved persons experiencing symptoms that resembled Major Depression Disorder (MDD) from this diagnosis. Now, in the DSM-5, this exclusion criterion has been removed and clinicians are encouraged to use their clinical judgment when encountering bereaved individuals who present these symptoms, which may be not only a normal response to a significant loss, but may indicate the presence of a major depressive episode (MDE). Six features are mentioned in the DSM-5 to help clinicians to distinguish grief reactions from a MDE (5th ed.; DSM-5; American Psychiatric Association, 2013):

a) The predominant affect of grief is feelings of emptiness and loss while in MDE the core affect is a persistent depressed mood and inability to anticipate happiness.
b) The dysphoria in grief gradually disappears in weeks and usually occurs in pangs commonly associated with thoughts of the deceased, while in MDE the dysphoria is persistent and not associated with specific thoughts or preoccupations.
c) Bereaved people may experience positive emotions and humor, which is uncharacteristic of MDE.
d) The content of thinking in bereaved individuals is related to memories of the deceased. In MDE the thought content is self-critical or consisting of pessimistic ruminations.
e) Bereaved people generally preserve their self-esteem while individuals with a MDE present feelings of worthlessness and self-loathing.
f) In bereaved individuals, thoughts of death and dying are generally focused on “joining the deceased”, while in MDE thoughts are related to ending one’s own life.

* See a Mindmap of the DSM-5 diagnostic criteria for Major Depressive Disorder on page 8.

2.2.2 Posttraumatic stress and Anxiety disorders after losing a loved one

Previous versions of the DSM excluded “normal” bereavement (i.e. anticipated and non-sudden) from criterion A, which is the stressor criterion (Sidney Zisook et al., 2014). Nowadays, the DSM-5 has extended this criterion to include indirect exposure to a violent or accidental trauma or death (5th ed.; DSM-5; American Psychiatric Association, 2013). A systematic review including studies on widowed individuals found a prevalence of PTSD of 11.8% during the first year of bereavement. However, this prevalence decreased with time after the loss (Onrust & Cuijpers, 2006). Another study found that violent and unnatural deaths were predictive of PTSD symptoms in contrast with sudden deaths from natural causes, such as heart attacks, which did not predict PTSD (Kaltman & Bonanno, 2003). There is paucity of research concerning other anxiety disorders such as Panic Disorder (PD) and Generalized Anxiety Disorder (GAD) in the context of grief. However, those few studies that are available suggest higher risk for PD and GAD in bereaved populations when compared with community samples (S. Jacobs et al., 1990; Shear & Skritskaya, 2012).

* See a Mindmap of the DSM-5 diagnostic criteria for PTSD on page 9.

Figure 2. Mindmap of the Diagnostic Criteria of Major Depression Disorder (DSM-5)

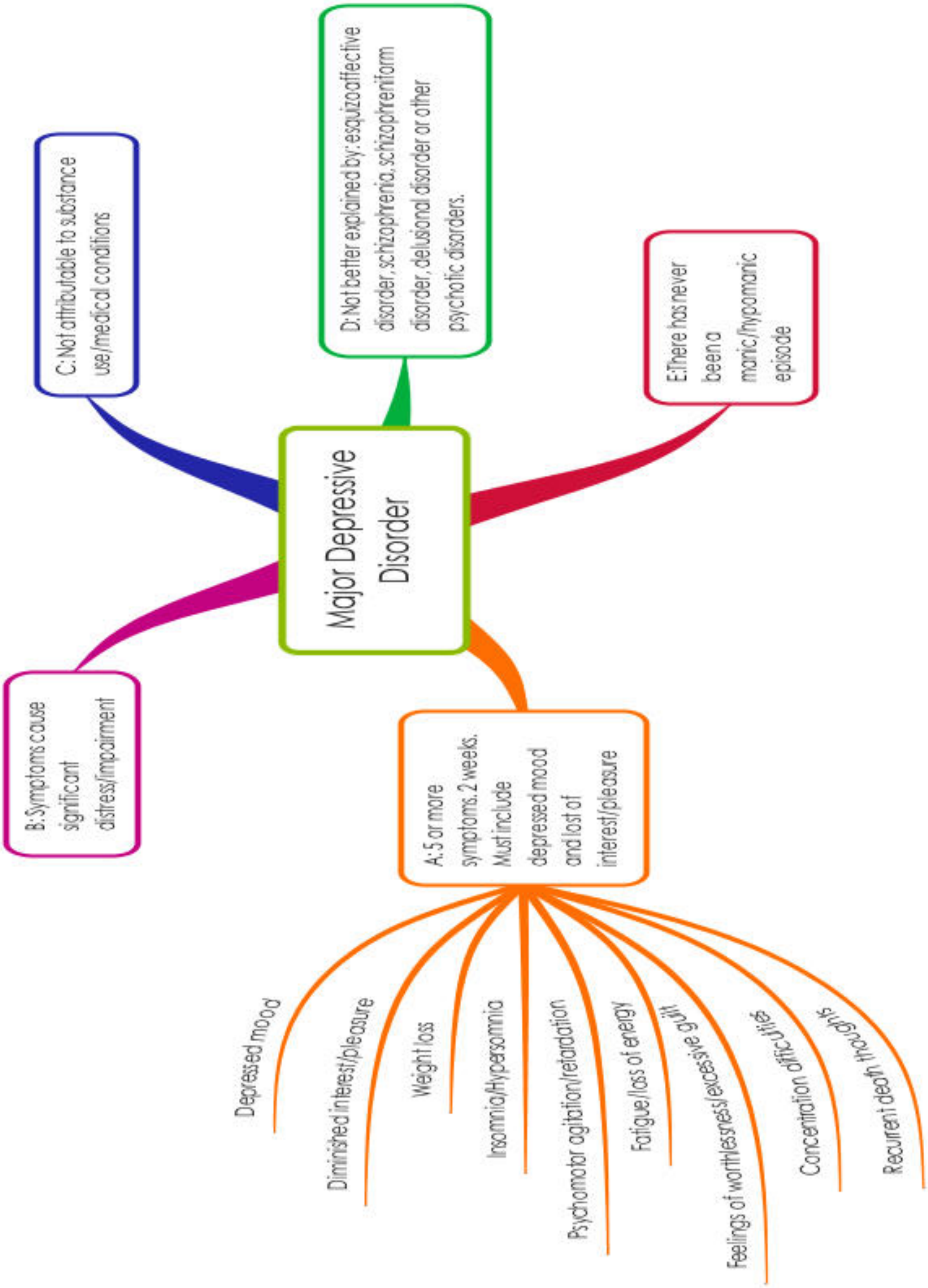
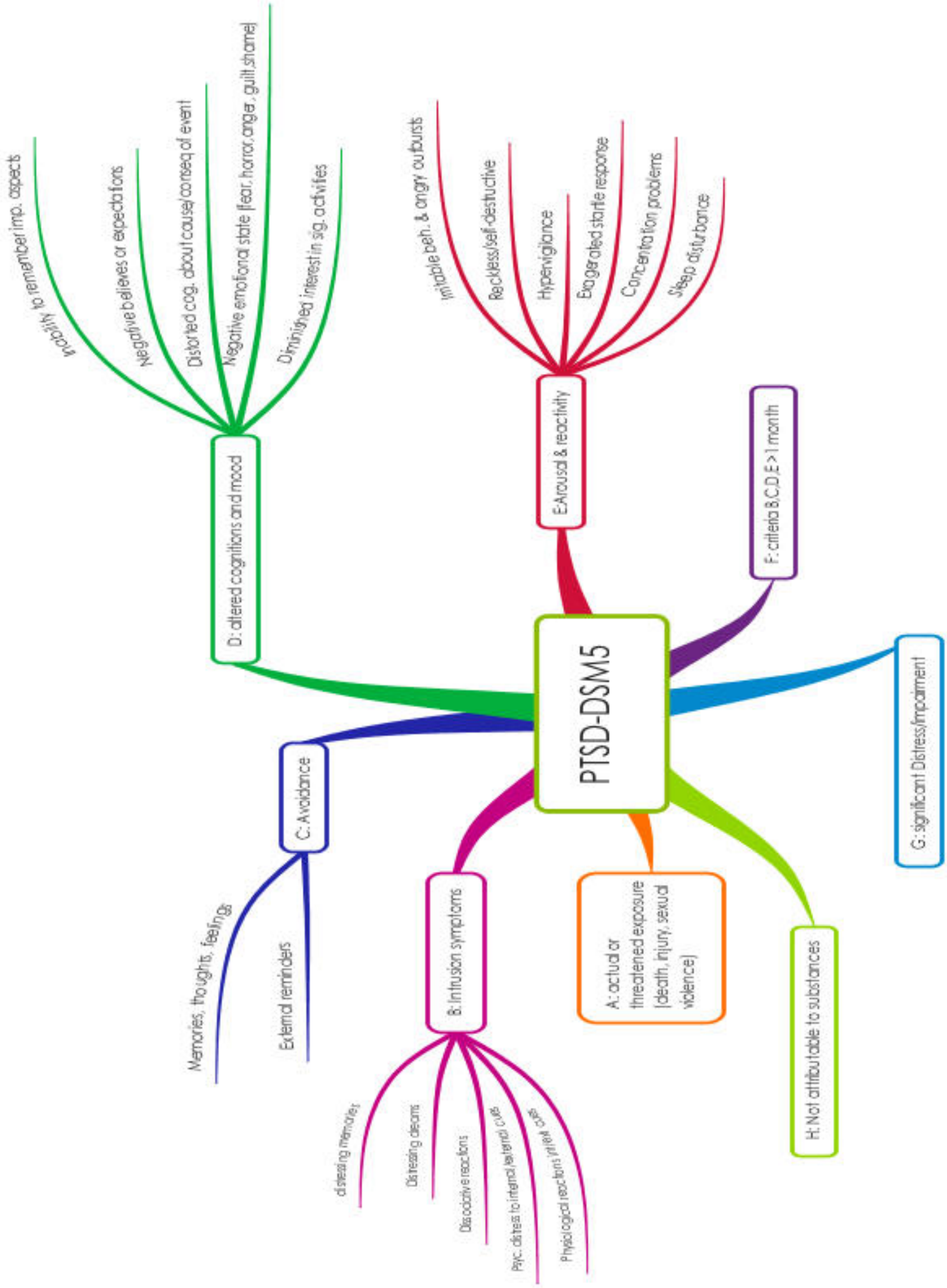


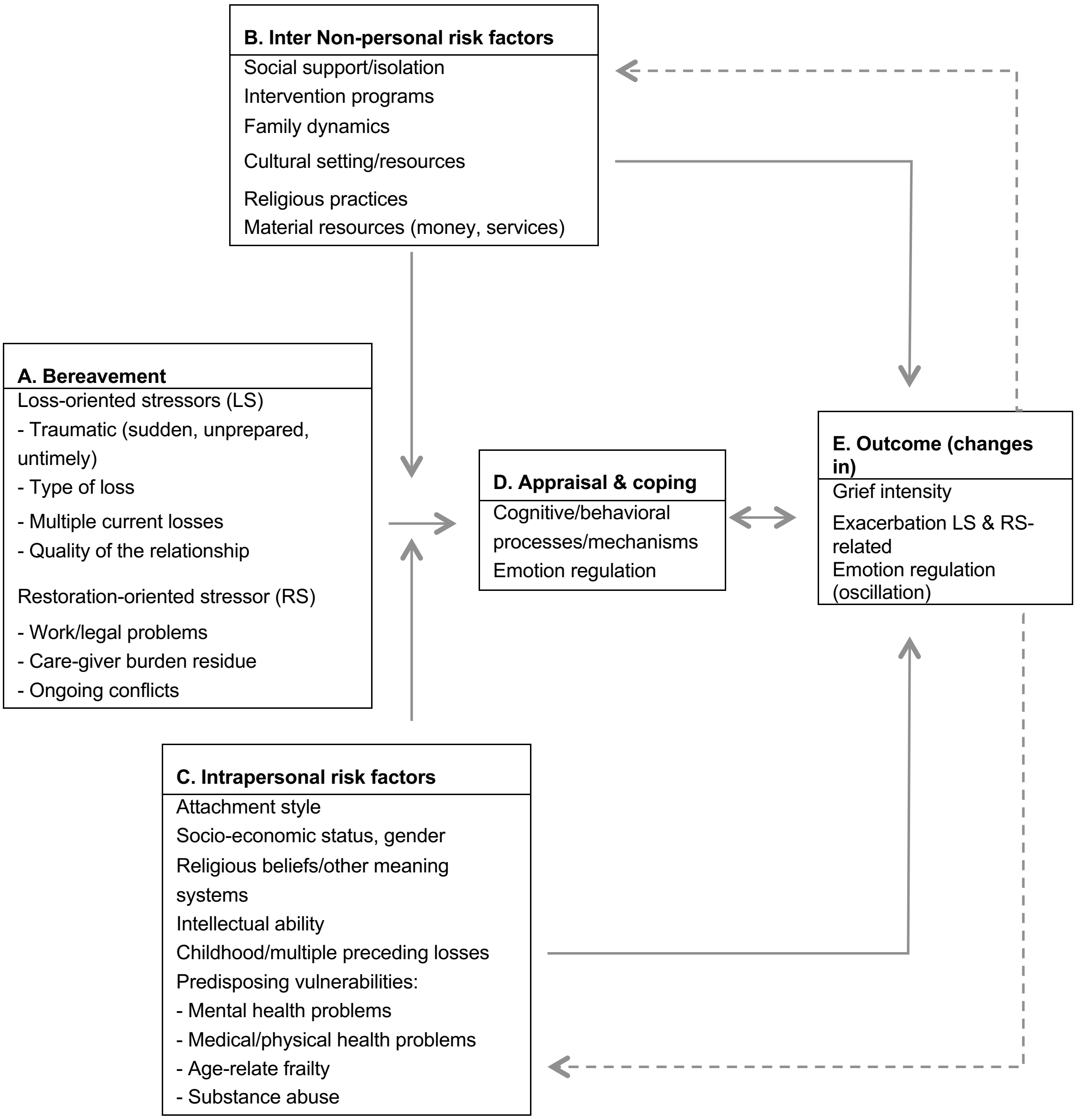
Figure 3. Mindmap of the Diagnostic Criteria of Posttraumatic Stress Disorder (DSM-5)



2.2.3 RISK FACTORS OF BEREAVEMENT OUTCOME

There are individual differences in adaptation to bereavement. What makes an individual vulnerable for experiencing a negative outcome of bereavement has been the subject of research. According to the integrative risk factor framework for the prediction of bereavement outcome (Stroebe et al., 2006), to understand individual differences, it is necessary to define and analyze: (a) the stressors that people experience in relation to their bereavement; (b) how these stressors are appraised in terms of the significance and the demands of the situation as well as (c) the available resources to cope with these stressing demands (Stroebe et al., 2006). As contributors to the differences in bereavement outcome, this framework includes the nature of the stressor, interpersonal resources, intrapersonal resources, coping and appraisal processes and the grief outcomes (Figure 5).

Figure 4. The integrative risk factor framework for the prediction of bereavement outcome (Stroebe et al. 2006). Reproduced with permission from the Copyright Clearance Center at Elsevier.



2.3 GRIEF AFTER SUDDEN AND VIOLENT LOSSES

Sudden and violent losses include deaths from accidents, suicides and homicides. Disaster and war-related deaths may also be included (Kristensen, Weisæth, & Heir, 2012). Two components seem to be potentially traumatizing after fatal accidents, suicides and homicides. The first one is the suddenness of the loss and the other is the violence of the death. These components distinguish these potentially traumatic losses from loss through natural deaths (Currier, Holland, & Neimeyer, 2006) . Although it is unclear if suddenness alone increases the risk for grief complications, in the case of suicides and homicides, violence was willing and intentional, whether from part of the perpetrator (homicide) or the deceased (suicide). Other common features that distinguish sudden and violent losses from natural death losses can be media coverage and contact with the criminal justice system (Hawton & Simkin, 2003).

People bereaved by sudden and violent deaths often display symptoms contrary to the resilience that the majority of other bereaved display (Bonanno, Norman and Nesse, 2004). A recent review of various empirical studies of individuals bereaved by sudden and violent losses found that these individuals present a wide variety of mental health problems such as Prolonged Grief Disorder (PGD), Major Depressive Disorder (MDD), Posttraumatic Stress Disorder (PTSD), alcohol and drug abuse or dependence, and suicidal ideation (Kristensen et al., 2012).

2.4 COMPLICATED GRIEF

The condition of Complicated Grief (CG) is also called Prolonged Grief Disorder (PGD) (Prigerson et al., 2009a). This condition can follow the loss of any close relationship and it is characterized by the intensity of grief, which lasts longer than expected according to social norms and that causes impairment in daily functioning (Shear, 2015). During the course of the first months after the loss of a loved one, acute grief and CG share similar symptoms. However, by approximately the 6th month after the loss, the majority of the bereaved persons are able to accept the reality of the death, they can see the possibility of having satisfying relationships in the future, their self-esteem and sense of competence are not adversely affected, they have the ability to be productive at work, and are able to feel joy and have a sense of purpose and meaning in their lives (Zhang, El-Jawahri, & Prigerson, 2006). In contrast, individuals with CG experience intense yearning for the deceased person, recurrent, intrusive and distressing thoughts about the absence of the deceased, feelings of emptiness and little hope regarding experiencing joy in the future. Also, they present feelings of being disconnected from people who previously were considered as to be in close relationships with. People suffering with CG are preoccupied by their loss and may present anger or guilt-related ruminations in relation to the circumstances of the loved one’s death. Also, they experience lack of meaning and purpose in life without the deceased (Shear, 2015; Zhang et al., 2006).

The prevalence of complicated grief in the general population ranges between 2.4% and 4.8% (Fujisawa et al., 2010; Kersting, Brähler, Glaesmer, & Wagner, 2011) and it is more common in women than in men. The symptoms can appear during the first months after the loved one's death or after various months or even years. Individuals of any age can suffer from complicated grief. In the case of adults, the DSM-5 recommends the diagnosis to be used after 12 months in order to differentiate it from acute grief. However, in the case of children this diagnosis can be used when the symptoms have been persistently present for 6 months (5th ed.; DSM-5; American Psychiatric Association, 2013). Longitudinal studies have shown an association of CG with psychiatric diagnoses such as MDD, PTSD or GAD, suicidal ideation, functional disability and low quality of life at 6-12 months pots loss even after controlling for depression and anxiety (Prigerson et al., 2009b). There is also research showing that CG is more likely to occur after sudden or violent types of deaths like suicide (Mitchell, Kim, Prigerson, & Mortimer-Stephens, 2004; Tal Young et al., 2012), homicide (Denderen et al., 2013) and accidents (Nakajima, Ito, Shirai, & Konishi, 2012). Factor analyses have repeatedly shown that the core component of PGD is the persisting yearning for the deceased and that this component makes PGD a condition that is distinguishable from MDD and PTSD (Maercker et al., 2013). Avoidance of feared stimuli associated with psychological trauma and hypervigilance are not present in CG as they are in PTSD. On the other hand, distress caused by the separation from the deceased, longing, and worrying about being abandoned are not present in the diagnostic criteria for PTSD. However, traumatic losses may cause psychological conditions in which both, CG and PTSD co-occur. Sadness, diminished interest and pleasure in activities and psychomotor retardation are present in MDD whereas yearning for the deceased and not "moving on" beyond the loss are indicators of CG (Zhang et al., 2006).

Two research groups have proposed the inclusion of this condition in the DSM-5 as Prolonged Grief Disorder (Prigerson, 2009) and Complicated Grief (Shear et al. 2011). PGD is also a diagnosis currently proposed to be included in the ICD-11 in 2015 (Maercker et al, 2013). The DSM-5 includes, under the section called *Conditions for further study,* Persistent Complex Bereavement Disorder (PCBD). The criteria of PCBD are very similar to PGD and CG but as all the disorders classified in the DSM-5 as conditions for further study, the diagnosis of PCBD is not intended for clinical use (American Psychiatric Association, 2013).

2.5 THE SUICIDE OF A CHILD IN A FAMILY

Suicide-bereaved parents and siblings face the fact that, in addition to the devastating experience of losing a child or a sibling, the death was intentional and seemed to be self-inflicted. The family dynamics are changed and the parents' physical, social and psychological suffering become the context for the bereaved siblings (K. Dyregrov & Dyregrov, 2005). Besides, when the death cause is suicide, the family is likely to be exposed to additional stressors such as legal procedures, contact with authorities, police, health professionals, media, etcetera (Hawton & Simkin, 2003).

The high risk for health complications associated to their grief, makes suicide-bereaved parents a vulnerable group. Studies show that after losing a child to suicide, bereaved parents are at high risk of experiencing symptoms of post-traumatic stress (Murphy, Johnson, Chung, & Beaton, 2003), depression, anxiety as well as taking their own lives (Qin, Agerbo, & Mortensen, 2002). Tallying to these complications, suicide-bereaved couples are at an increased risk for marital break-up (Bolton et al., 2013). Problems associated to suicide-bereavement such as experiencing stigmatization and feelings of guilt and shame (Hawton & Simkin, 2003; Omerov, Steineck, Nyberg, Runeson, & Nyberg, 2013) may exacerbate the intensity of grief in suicide-bereaved parents. These conditions often call for professional interventions in order to avoid negative health outcomes and even premature death in the suicide-bereaved parents (Tal Young et al., 2012).

Losing a sibling to suicide is a calamitous event, which is associated with high risk for psychiatric morbidity such as depression, anxiety, and symptoms of posttraumatic stress disorder in the bereaved siblings (de Groot, Keijser & Neeleman, 2006; Kessing, Agerbo, E., & Mortensen, 2003; Mitchell, Kim, Prigerson, & Mortimer-Stephens, 2004). Grief in suicide-bereaved siblings is characterized by constant feelings of guilt (Dyregrov & Dyregrov, 2005), sleep problems, impaired functioning in social situations (Sethi & Bhargava, 2003), academic difficulties (Dyregrov, 2009), and physical problems (Mitchell et al., 2004). Health professionals, who tend to concentrate their attention on the bereaved parents, may overlook the grief-related needs of the bereaved siblings. Furthermore, the bereaved siblings' needs may also be overlooked by their parents, whose psychological resources and mental strength are invested on trying to cope with their own grief. This is probably the reason why researchers have described suicide-bereaved siblings as "The forgotten bereaved" (K. Dyregrov & A. Dyregrov, 2005).

2.5.1 NEED OF PROFESSIONAL HELP AFTER A SUICIDE IN THE FAMILY

Estimates of the number of suicide survivors, meaning the people who are personally affected after the suicide of a loved one, vary widely from 6 to 60 per suicide, depending on how the term "suicide survivor" is defined (Berman, 2011). Existing research regarding estimates of the percentage of suicide survivors that needs professional help and actually receive it is sparse. An American study of 144 suicide-bereaved next-of-kin found that around 24% reported that they had received either formal or informal help after the loss, although many more (72%) had reported professional help as their desired type of help (Provini, Everett, & Pfeffer, 2000). Also, in a Norwegian study including 179 suicide-bereaved parents, 88% expressed a need of professional help for bereavement-related difficulties, and 85% reported that they had received some form of contact with community professionals, althought 60% deemed this contact as insufficient due to its shortness (K. Dyregrov, 2002a). The suicide survivors' perceived need of professional help seems to be large but the received professional intervention, if any, seems to be insufficient. Some researchers are of the opinion that, in many contexts, receiving professional help is a random event for the suicide-bereaved (J R Jordan, 2001; Wilson & Marshall, 2010).

There is great variability in the way bereaved family members respond to the loss of a loved one. Some will experience years of physical, psychological and existential suffering while others will respond with significant resilience (Bonanno et al., 2002). However, research indicates that highly distressed bereaved individuals would benefit from professional interventions (Currier, Neimeyer, & Berman, 2008). Suicide postvention or interventions for the suicide-bereaved are considered to be a powerful form of primary and secondary prevention given that suicide-bereaved individuals are at risk for many physical and psychological complications (Andriessen, 2009; John R Jordan & McMenamy, 2004).

Available professional help for the suicide-bereaved in Sweden is received via public mental help centers, helplines, primary care providers, psychosocial crisis teams, private mental health professionals and professionals especialized in grief. Still, the Swedish healthcare system does not always employ an active postvention model, which consists of health professionals reaching out to the bereaved as close to the time of the loss as possible (Cerel & Campbell, 2008). Instead, receiving professional help often depends on the bereaved searching for it, which is in contradiction with what research indicates concerning what suicide-bereaved individuals wish from health professionals (K. Dyregrov, 2009).

Currently, we know very little regarding what interventions may be the most helpful for suicide-bereaved individuals and at which point since the loss these interventions should be provided. Known barriers to professional help-seeking in suicide-bereaved individuals are depression, lack of information about where to find help, unavailability of resources (McMenamy, Jordan, & Mitchell, 2008), and as our research suggests, lack of trust in the healthcare system.

2.6 TRUST

Trust is a personal attitude that works as an important part of social systems and also as a social determinant of health in the population (Ahnquist, Wamala, & Lindström, 2010). Trust can be horizontal (interpersonal trust) or vertical (trust in institutions). Two characteristics are inherent to trust: (a) It entails the optimistic acceptance of *vulnerability* from the trustor in front of the trustee, and (b) The trustor holds the confident *expectation* that the trustee (an individual or an institution) will act in the trustor's best interests (Hall, Dugan, Zheng, & Mishra, 2001).

Despite being closely related, it is important to distinguish trust from *satisfaction*. Trust is an evaluation oriented towards the future and satisfaction is an evaluation of past events. For example, trusting patients are more likely to be satisfied with the received interventions and satisfying previous encounters are likely to foster greater trust (Hall et al., 2001). Trust has shown to be a better predictor than satisfaction whether patients remain with their doctor and adhere treatment (Thom & Campbell, 1997).

Together with other Nordic countries, Sweden ranks as one of the countries with the highest interpersonal and institutional trust in the world (Morrone, Tontoranelli, & Ranuzzi, 2009). Also, Sweden ranks as a society with one of the highest levels of secular, rational and self-expression values, where among other characteristics, autonomy and individual solution to problems are more common practice than community solutions (Inglehart & Welzel, 2005).

2.6.1 Distrust

There are three possible meanings of *distrust*: (a) Low level or absence of trust, which is not the same as active distrust, (b) Distrust as the opposite of trust including components of suspicion and pessimistic expectations, and (c) Distrust as a complement of trust. It includes trust and distrust at the same time, the “trust but verify” attitude (Hall et al., 2001). In the present thesis, we used the first of these meanings and decided to call our outcome variable “Lack of trust” to refer to suicide-bereaved parents’ low level or absence of trust in the healthcare system (study III).

2.6.2 Trust in the healthcare system

Within the healthcare system the concept of vulnerability is intrinsic. Ill persons are, on one hand, inherently vulnerable emotionally, physically, spiritually and in some cases also financially. On the other hand, they are also vulnerable with regard to the imbalance of knowledge and power that characterizes the interactions between health seekers and heath service providers (Goold, 2002). Trust in the healthcare system refers to the patient’s expectation that the healthcare services (trustee) will act in the patients’ (trustor) best interests. It means that the patient expects that the healthcare system will provide their services competently, responsibly, honesty, ethically and with concern.

Trust in the healthcare system matters because:

a) Trust in providers encourages the use of health services and also promotes patient’s behaviors which are important for effective treatment such as disclosure of symptoms, adherence to therapy, medication compliance, necessary behavioral changes, etcetera.
b) A health-system founded in trusting relationships generates wider social value. This means that health systems do not just produce health but also establish social norms that produce the basis for generalized trust and a sense of unity in a society.

On the contrary, very low trust or no trust at all in the healthcare system is associated with poor health outcomes such as increased risk of psychological distress (Ahnquist et al., 2010), low self-rated health (Armstrong et al., 2006), increased risk for daily smoking

(Lindström & Janzon, 2007) and decreased likelihood to undergo screening for life-threatening diseases (Yang, Matthews, & Hillemeier, 2011).

In the Swedish general population, the prevalence of very high trust in the healthcare system is 15%, rather high trust is 59%, no high trust or no trust at all 25%, no opinion 1% (Lindström & Janzon, 2007), suggesting that the baseline of trust in the healthcare system is rather high.

2.6.3 Predictors of trust in the healthcare system

Most studies show inconsistent results concerning the association between patient's characteristics and trust. Only age has a modest, positive correlation with trust (Hall et al., 2001). Still, we do not know if this correlation is due to a generational effect or to the fact that older people have more contact with health professionals. Patient's personality factors are not strong predictors of trust (Kao, Green, Zaslavsky, Koplan, & Cleary, 1998; Thom, Ribisl, Stewart, & Luke, 1999) and racial minority groups show distrust in the health services (E. A. Jacobs et al., 2011).

Considering the physician's characteristics, trust is consistently associated with physician's communication style and interpersonal skills (Aruguete & Roberts, 2002). Patient satisfaction, continuity of care, reliability in doctors fulfilling promises, valued listening time (Laugharne, Priebe, McCabe, Garland, & Clifford, 2012), clear communication and the possibility to chose one's physician are also positively associated with trust and adherence to medication (Maidment, Brown, & Calnan, 2011).

3 AIMS

The overall aim of our studies is to improve the professional care of suicide-bereaved families with a special focus on parents and siblings. This thesis explores help-seeking behavior in suicide bereaved siblings and also identifies and describes some areas of interest that can be seen as first steps towards improving the care provided to suicide-bereaved parents.

The specific aims of this thesis were:

- To identify areas of study (refining hypotheses) and to create a questionnaire that assesses factors that may contribute to long-term psychological distress in suicide-bereaved parents (Study I).
- To increase the understanding of suicide-bereaved siblings' professional help seeking behavior (Study II).
- To assess the prevalence of lack of trust in the healthcare system in suicide-bereaved parents and the variables associated with their lack of trust (Study III).
- To investigate if confronting the body at the scene of the suicide is associated with higher prevalence of psychological morbidity in suicide-bereaved parents (Study IV).

4 SUBJECTS AND METHODS

4.1 OVERVIEW

This doctoral thesis includes four scientific studies that employ a method developed at the Division of Clinical Cancer Epidemiology (Steineck, 2006) which has been used in different nation-wide studies of bereaved populations (Kreicbergs, 2004; Hauksdottir, 2006; Rådestad 2007; Omerov, 2013). Our research includes a preparatory phase (study I and II) and a nation-wide main study (study III and IV).

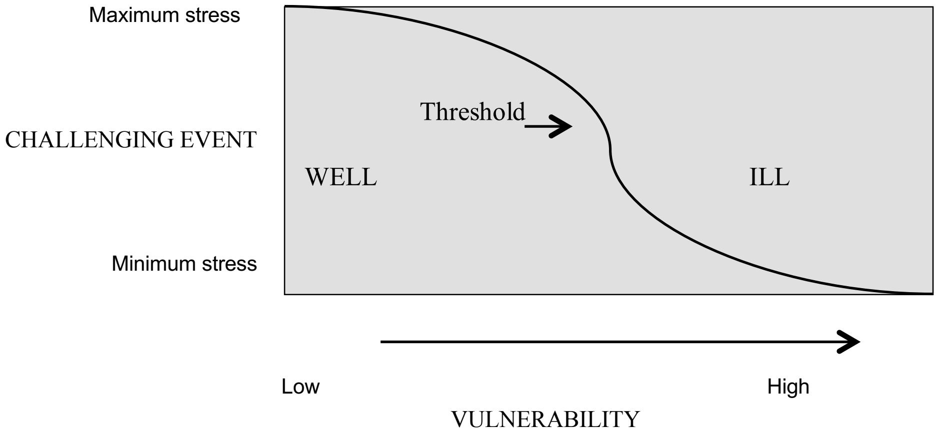
Table 2. Overview of the studies included in this thesis

	Study I	**Study II**	**Study III**	**Study IV**
Aims	(a) To refine our working hypotheses and to create a study-specific questionnaire, (b) To test the questionnaire and the data collection procedures	To increase our understanding of suicide-bereaved siblings' reasons for seeking or not professional support, factors determining their (dis)satisfaction with the received help and their recommendations to health providers	To investigate the occurrence and variables associated to lack of trust in the healthcare system in suicide-bereaved parents 2-5 years after their loss	To investigate if confronting the body at the scene of death is associated with higher prevalence of psychological morbidity in suicide-bereaved parents 2-5 years after their loss
Design	Methodological study	Qualitative study	Population-based nation-wide survey	Population-based nation-wide survey
Population	17 suicide-bereaved parents for the interviews. 46 suicide-bereaved parents for the validation of questionnaire. 79 suicide-bereaved parents for the pilot study	18 suicide-bereaved siblings	569 suicide-bereaved parents and a matched comparison group of 326 non-bereaved parents	666 suicide-bereaved parents
Main outcome measures	NA	NA	Lack of trust in the healthcare system	Psychological morbidity
Data analyses	Qualitative content analysis	Qualitative content analysis	Binomial regression and multivariable modeling	Binomial regression and multivariable modeling

4.2 CONCEPTUAL FRAMEWORK

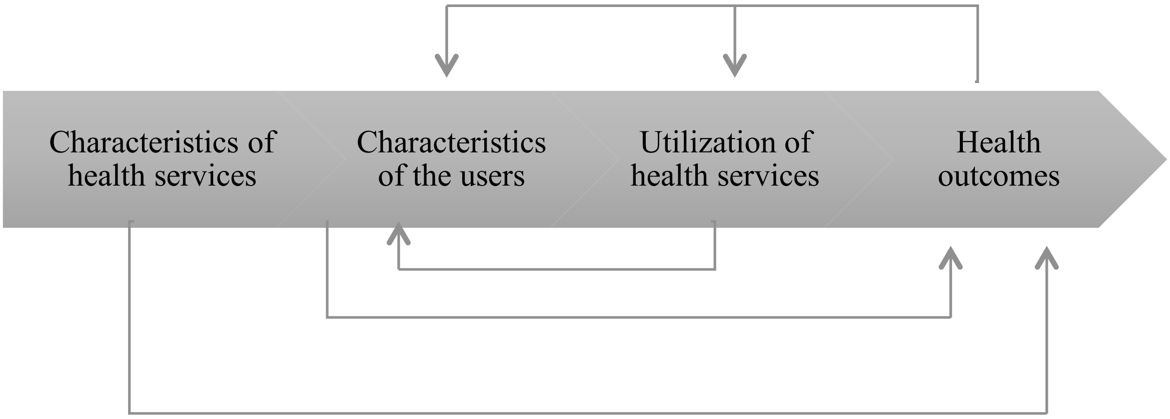
We have used various conceptual frameworks that have served as departing points in the different studies included in this thesis. These frameworks have contributed to the understanding of the different phenomena that we have investigated, such as suicide-bereavement in the family, lack of trust in the healthcare system, help-seeking behavior among suicide-bereaved siblings, and traumatic reactions after discovering the body of one's child at the site of death. Since the main aim of our studies is to improve the professional care of suicide-bereaved families, the principal focus of this thesis has been vulnerability (i.e. What variables are associated to lack of trust in the health services in suicide-bereaved parents?) and negative health outcomes (i.e. Do parents who confront the body of their dead child present higher psychological morbidity?) instead of focusing on grief as a process. During our research concerning suicide-bereavement, lack of trust in the health services in suicide-bereaved parents and confronting the child's body at the site of the suicide, we used the Stress-vulnerability model (Zubin & Spring, 1977) and the Integrative risk factor framework for the prediction of bereavement outcome (M. S. Stroebe et al., 2006), the latter has been previously described under Risk-factors of bereavement (See section 2.2.3 in this thesis). Based on previous research, Zubin and Spring (1977) asserted that life event stressors, such as bereavement, are challenging for the individual, demand readjustment or re-organization in the person's life and are likely to elicit physical and psychological problems. The stress produced by the stressing event activates the individual's adaptive skills. The individual's adaptation to the stressing event will depend on their personal threshold to cope with stress. The lower the threshold, the higher their vulnerability for psychological or physical morbidity.

Figure 5. Stress- vulnerability model. Adapted from Zubing & Spring (1977)



When investigating the suicide-bereaved siblings' perceptions of the health system and their reasons for seeking or not seeking professional help (study II), we were inspired by the Behavioral Model of Health (Andersen, 1995). This model helped us to understand the different pathways of health services' use. However, we did not test the model itself in our study because this was not our aim. Andersen's Behavioral Model of Health asserts that the use of health services is a dynamic process that includes *characteristics of the health services* (policies, resources and organization of health services); *characteristics of the users* (such as predisposing characteristics, enabling resources such as being able to afford medical care and knowing where to seek for help, and self-assessed and evaluated need of professional help); *health behaviors that lead to utilization of health services* (personal health practices); as well as *health outcomes* (self-perceived and professionally-evaluated health status, and consumer satisfaction). Together, these dimensions interact to influence the predisposition, quantity and likelihood of health service use.

Figure 6. Flowchart explaining the Behavioral Model of Access to healthcare (Andersen, 1993)



4.3 PREPARATORY PHASE

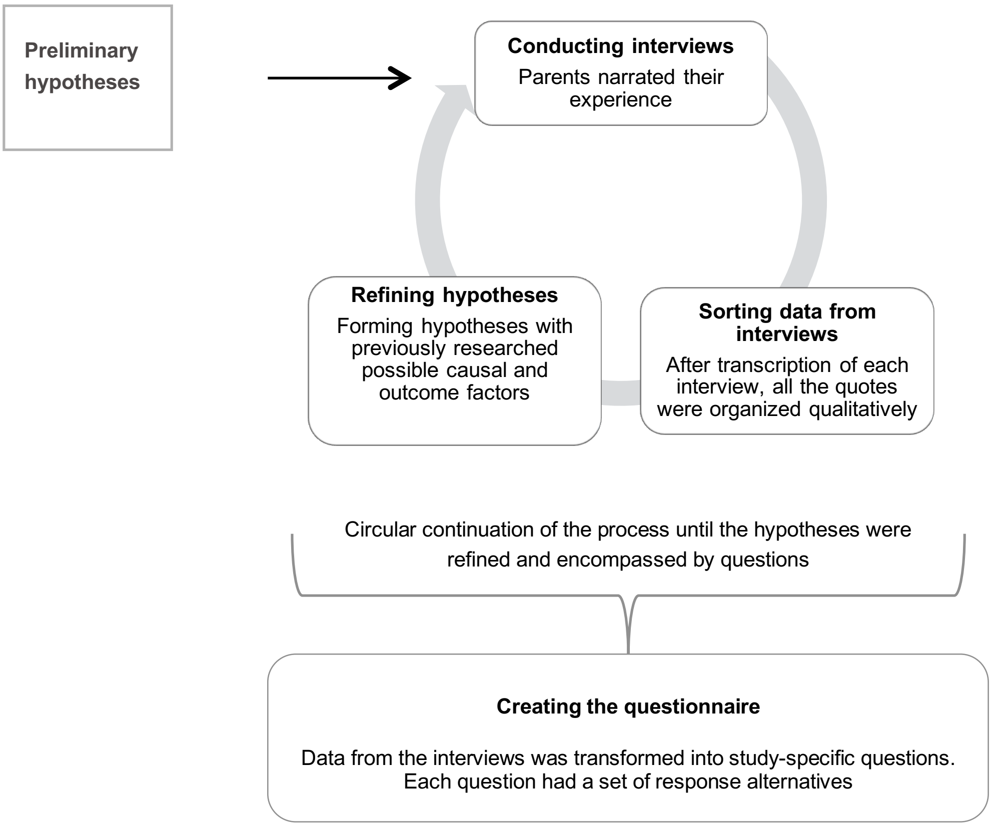
4.3.1 Study I. Preparatory studies to a population-based survey of suicide-bereaved parents in Sweden

When choosing the method to investigate a sensitive and vulnerable population, like the suicide-bereaved, observational methods are usually preferred instead of experimental ones due to ethical reasons. Obtaining a high participation rate is essential to draw valid conclusions of a study but this can be very difficult to achieve when we want to investigate suicide-bereaved individuals using potentially painful questions (WHO, 2011). For ethical reasons, we did not consider employing common measures known to increase participation rates like economically awarding participation, providing freebies or mentioning a responsibility to take part in the study. Instead, we used thoroughly evaluated data collection procedures. Another vital part in the design of our study was to avoid sampling bias through self-selection (Forte, Hill, Pazder, & Feudtner, 2004). This is why we decided to use a nation-wide unselected population of suicide-bereaved parents, which is considered to be representative. The aim of the preparatory study was twofold: (a) To refine our working hypotheses in order to create a study-specific questionnaire, which includes study-specific questions, and (b) To test the questionnaire and data collection procedures. We tested the questionnaire in a pilot study in order to test participation rate and logistics as well as to make sure there were no harmful effects of the survey (Kreicbergs, Valdimarsdóttir, Steineck, & Henter, 2004). In other words, following the methodological tradition of our research group for the study of bereaved populations, we performed qualitative interviews in order to identify areas that need improvement for the bereaved relatives, and then, in order to measure what we found in the interviews, we constructed a study-specific questionnaire.

4.3.2 Refining our working hypotheses and creating a study specific questionnaire

In the beginning of this study, we worked with preliminary hypotheses regarding what we believed could be helpful for suicide-bereaved parents. These hypotheses came from scientific literature, clinical experience, conversations with suicide-bereaved individuals and from discussions with grief and suicidology experts. The process of hypotheses refinement was done to formulate the questions that would be included in our study-specific questionnaire. The refinement of our preliminary hypotheses was performed in a circular fashion with the help of the qualitative content analysis of 17 interviews with suicide-bereaved parents. Starting with our preliminary hypotheses, we conducted interviews, one at the time and then we qualitatively sorted the content of the interview. Based on the qualitative sorting we refined the hypotheses and conducted new interviews until the hypotheses could be formulated as questions to be included in our questionnaire (figure 7).

Figure 7. Process for creating our questionnaire



4.3.3 The participants

We identified the participants by means of purposive sampling (Polit, D & Beck, C; 2008). The inclusion criterion was loss of an offspring aged 15 to 30 years old to suicide 2-5 years before the interview. Based on previous research reporting that significant bereavement phenomena can still be present at 24 months after the loss (Prigerson, H. & Jacobs, S; 2001), we chose the inclusion criterion of bereavement of at least two years previously in order to avoid our results being biased by the recentness of the loss. We identified 4 participants through records from a psychiatric department in Stockholm, 12 through the Swedish self-help organization for suicide survivors (SPES) and 1 through a local newspaper advertisement about the study. Eleven of the participants were mothers and 6 fathers and their ages ranged between 51-78 years. From this set of parents, 6 were couples. Three mothers, who were divorced, lived alone. The rest lived together with the other parent of the deceased child. The lost offspring was male in 12 cases and female in 5. Three of them were living in the parental house at the time of their death, while the others had left the parental home. The age of the offspring ranged between 16-26 years at the time of death. At the time of the interview, the 3 divorced mothers, a married mother and 1 couple lived in large towns, 3 other couples lived in towns, and 2 couples and a divorced mother lived in the countryside. They were interviewed separately and in the case of two couples, only the mothers were interviewed. One son was adopted and one couple had lost two sons to suicide.

4.3.4.The narrative interviews

We started by sending an introductory letter to the participants, which explained that the purpose of the study was to improve our knowledge concerning the health and needs of suicide-bereaved parents and that the material would be used for research purposes. The letter also included the researchers' contact information and indicated that participation could be emotionally difficult, that it was voluntary, and could be withdrawn at any time without the need for further explanation. Participants were asked if the interview could be recorded and if the analysis of their interviews could be used for research purposes. All consented. All interviews began by asking the participants *"Can you tell me about your son/daughter?"* In this fashion, the interviews took the form of narratives in most cases (Jovchelovitch, S. & Bauer, M; 2000). Parents started by telling about the time before the offspring's death, then the time surrounding the suicide and lastly, the time after the suicide.

4.3.5 Qualitative analysis of the interviews

In order to observe if the interviewed parents brought up new areas that had not yet been covered by our hypotheses, and also to use the parents' own wordings when formulating the questions, we performed a qualitative analysis of the interviews.

We were inspired by the procedures of Graneheim & Lundman's (2004) to analyze the content of the interviews in the following sequence:

a) Transcribing the interviews word by word.
b) Labeling with a code sections with similar content and dividing them as meaning units.
c) Summarizing the meaning units into their core meaning and sorting them according to various codes.
d) Arranging the various codes into categories and sub-categories
e) Qualitatively interpreting the collected information and go through the previous steps for each new interview until no new codes could be identified (saturation).
f) Contrasting the codes vis-à-vis previous research findings while refining the hypotheses and developing a questionnaire.

We achieved saturation, meaning that no new data emerged from the interviews, after 17 interviews were performed. By then, the questionnaire draft included 306 questions, and we divided them chronologically according to how the parents organized their narratives when they told their story to the interviewer: The time previous to the death of the child, the time surrounding his/her suicide, and the time ensuing the death of their child.

4.3.6 Formulating and ordering the questions to be included in the questionnaire

We formulated each question with the object to assess only one conceptual-entity and to be answered by only one response alternative. In this process, we retained the same wording that the parents used when we interviewed them in this preparatory study. When we constructed the questionnaire, we decided to use response alternatives in sets that had been previously assessed and used in other studies of bereaved populations in our research group (Onelöv et al., 2007; Skoogh et al., 2010; Steineck, Hunt, & Adolfsson, 2006). These sets of response alternatives were well understood by the bereaved parents in our preparatory study. Many questions were followed by space for free-hand comments with the objective to collect more fine-grained information about the conceptual entity being measured by that specific question. In this manner, our questionnaire allowed us to collect both quantitative and qualitative data. Regarding the order of the questions, we followed the findings of Hauksdóttir et al. (2006) who investigated the importance of the order of questions in 76 widowers whose wives had died 2-5 years earlier due to cancer. They found that widowers who answered questions about their present well-being after having responded questions regarding their wife's cancer and death, presented higher prevalence of psychological morbidity than widowers who responded to questions about their present well-being before answering questions about their wife's cancer and death. Consequently, we positioned the questions regarding current well-being, such as "Have you experienced your life as meaningful during the last month?", "How would you rate your quality of life has been during the last month?", "Have you taken medication to be able to sleep?" etcetera, as well as the psychometric scales PHQ-9 and GAD-2 at the beginning of the questionnaire.

Examples of the different sets of response alternatives:

a. Have you relived your child's death through nightmares during the last year?

☐ No
☐ Yes, occasionally
☐ Yes, 1-3 days per week
☐ Yes, 4-5 days per week
☐ Yes, 6-7 days per week
Please, tell us about your thoughts

____
____
____

b. Where you prepared for the suicide of your child when you found out that he or she had died?

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

Please, tell us more about your thoughts when you found out that he or she had died

____

____

____

c. Have you met friends or acquaintances during the last year?

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

4.3.7 Validating the questionnaire

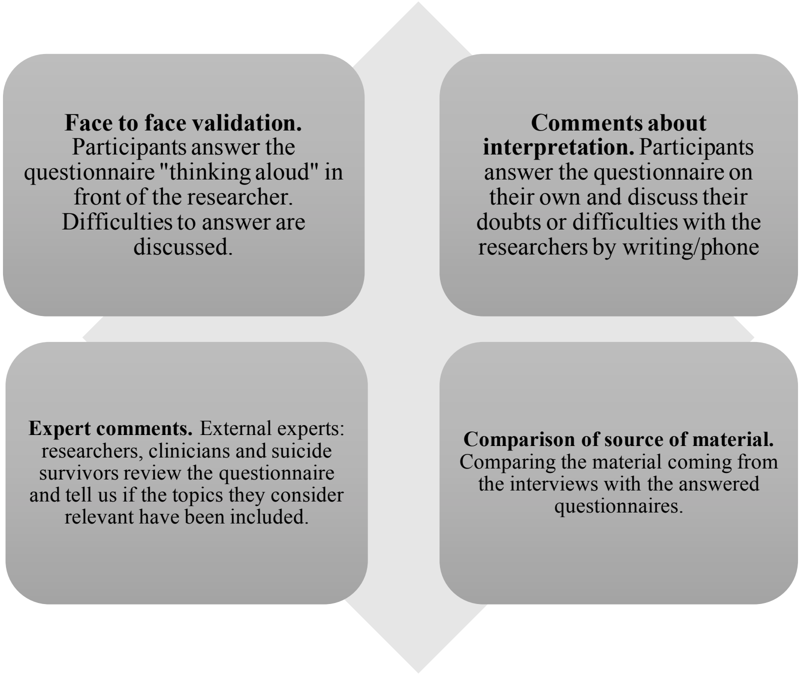
In total, 46 parents were included in the validation of the questionnaire: 29 were new to the study and 17 had already been interviewed. They fulfilled the inclusion criteria set for the main study (described below on page 30) and they were recruited from the Swedish self-help organization for suicide survivors, SPES (Note: “Suicide survivors” meaning the individuals bereaved by the suicide of a loved one). We used four different means of validation:

1) The participants (N=3) answered the questionnaire face-to-face with the researcher and voiced their comments about their understanding of the questions and response alternatives. The first three parents to go through this validation process were very expressive at the beginning but their level of energy and number of comments decreased with time. We therefore discarded this means of validation and replaced it by the other three shown below.
2) The participants (N=43) answered the questionnaire on their own while writing comments if they found a question to be unclear, difficult, offensive, upsetting or negative in any other way. The interviewer contacted these participants by phone and discussed their comments with them as well as the reasons for missing, multiple or unclear answers.
3) Comparison of the material from the interview with the questionnaire (N=17). The interviewer compared the answers given in the questionnaires with the information provided during the interviews. Then, she contacted these participants and discussed with them in case there were any incongruities that were found.
4) Expert comments about the content. In order to warrant that all important areas related to our hypotheses and research questions were included in the questionnaire, we invited external experts, suicide researchers and clinicians to review the questionnaire and provide their comments about the content. We also asked all the

parents involved in the validation process if they thought that all relevant issues concerning the loss of their child had been covered in the questionnaire.

This process continued until there were no concerns regarding interpretation or content. Once the validation of the questionnaire was performed, we proceeded with the pilot study.

Figure 8. Validation of the questionnaire. Adapted from Pernilla Larsson Omerov. Parents who have lost a son or daughter through suicide – towards improved care and restored psychological health. Doctoral thesis (2013)



Face to face validation. Participants answer the questionnaire "thinking aloud" in front of the researcher. Difficulties to answer are discussed.

Comments about interpretation. Participants answer the questionnaire on their own and discuss their doubts or difficulties with the researchers by writing/phone

Expert comments. External experts: researchers, clinicians and suicide survivors review the questionnaire and tell us if the topics they consider relevant have been included.

Comparison of source of material. Comparing the material coming from the interviews with the answered questionnaires.

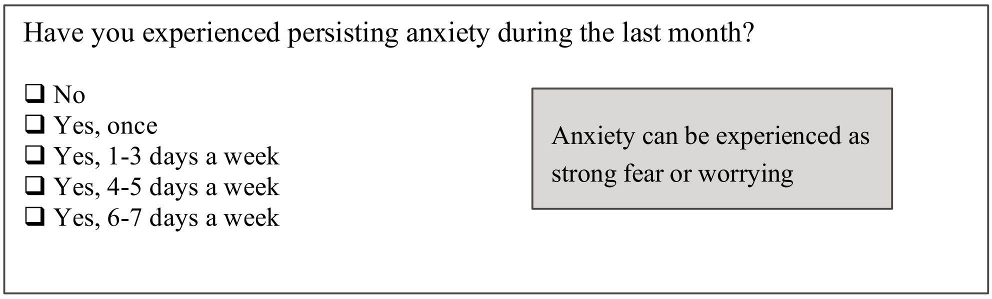
Pilot study

To assess harmful and beneficial effects of the survey and to test the participation rate and logistics, we included a sub-group of 79 parents from the study population. The answered questionnaires were answered by 60 of 79 (76%) contacted parents and we proceeded to perform the main data collection.

4.3.8 Testing and modifying the questionnaire

During the validation process, we became aware that some questions needed to be modified for the participants to understand them better. For example, regarding contact with professionals in relation to the death notice, we asked the parents if they had met a professional when they received the notice that their child had died. A bereaved father told us during the interview that he had received the death notice from the police. Still, when answering this question in the questionnaire, he marked the alternative “No.” When we asked him about this contradiction he explained that he did not consider that these policemen had acted professionally when giving the death notice to him. After this comment, we decided to include an information box in the questionnaire, which reads: “The word professional refers to a person who is professionally active for example, a policeman or a physician, and it does not refer to the person’s suitability or competence.” Another wording that was discussed by several participants and not widely accepted was “self murder”, which is the Swedish translation of “suicide”. The problem was that in Swedish, this word could acquire some criminal connotation. Furthermore, the term “suicide,” which does not have Swedish etymology and is less used than “self murder”, may be understood by some Swedish speakers as a word that is used when wanting to distance oneself from the topic, according to some parents. We deliberated these impressions with external experts and chose to use “Take his/her own life” when possible. If not, the word “self murder” was used, because it is the most common way of talking about suicide among non-professionals. The validation process also gave us the opportunity to see that some questions needed further clarification. With this purpose, we included information boxes to clarify some questions (For an example, see Figure 9). Furthermore, we observed that some parents needed to complement their answers and tell us more about their experience. This is why we included space for free comments. The first version of the questionnaire included 306 questions. Many parents told us that they considered it too long for them to complete. Consequently, we reduced the number of questions. The final version of the questionnaire included 196 questions some of them with sub-questions and space for free comments. For the non-bereaved parents, we constructed a shortened version of the questionnaire containing 93 questions, which included the psychometric scales and questions about health outcomes of interest such as well-being and daily life, and excluded questions related to the death of a child.

Figure 9. Example of information box



Have you experienced persisting anxiety during the last month?

☐ No
☐ Yes, once
☐ Yes, 1-3 days a week
☐ Yes, 4-5 days a week
☐ Yes, 6-7 days a week

Anxiety can be experienced as strong fear or worrying

4.3.9 Study population

Using the National Register of Causes of Death, we identified all individuals in Sweden that were between 15 and 30 years old (N=747) when they died by suicide (ICD-10 codes X60-84. Certain suicides) between 2004 and 2007. Using the Multi-generation Register we were able to identify their parents (N=918. Both, biological and non-biological parents were included). Then, using the Swedish Population Register we identified a comparison group of non-bereaved parents (N=508). The inclusion criteria for the bereaved parents were: to be alive, be born in any of the Nordic countries, loss of only one child, able to communicate in Swedish, and having a listed telephone number and address. The inclusion criteria for the comparison group, consisting of non-bereaved parents, were: to have a living child born the same year as the deceased child from the bereaved group, and to be matched (1:2) for sex, age, place of residence, marital status, and number of children. In order to comply with the strict Swedish law of secrecy, the register holders performed the identification of both groups and the matching. At the time when we received the contact information for all parents, we did not know who was bereaved and who was non-bereaved. Parents disclosed this information themselves when we contacted them by phone to asked if they were interested in participating in the study. In total, 915 bereaved and 508 non-bereaved parents were identified as eligible and we sent them an introductory letter. From all the eligible parents, we managed to get in contact with 1410 of 1423 (99%).

4.4 STUDY II. SUICIDE-BEREAVED SIBLINGS’ PERCEPTION OF HEALTH SERVICES

We performed interviews with suicide-bereaved siblings in order to create a questionnaire to be used in a nation-wide population survey of suicide-bereaved siblings which will be carried out in the near future. From the data collected in the interviews, we obtained insight into how individuas that lose a brother or sister to suicide perceive the health services. We also explored their rationales for seeking or not seeking professional help.

4.4.1 Study participants

We recruited suicide-bereaved siblings through mental health professionals, at conferences about suicide bereavement, through the Swedish self-help organization for suicide survivors (SPES) and through recommendations from some of those who had accepted to participate. We told potential participants that we would perform a study concerning the experience of losing a sibling to suicide and that all those interested in participating in the study could email or call the interviewer. Those who did so were asked if they had any questions regarding the study and to agree on a meeting place for the interview according to their preferences. The participants lived in different areas in Sweden therefore, the place of the interviews varied geographically at a national level, in this way conforming a maximun variation sample (Polit & Beck, 2008).

Before the interviews, the interviewer let the participants know that the information that they provided would be treated confidentially and that their personal details would be handled anonymously. They were also told that they had the right to stop or withdraw from the interview at any time without further explanation. After reciving this information, all participants gave oral consent to proceed with the interviews. After each interview, the content was analyzed using qualitative content analysis. We stopped the recruitment of participants after interviewing 18 bereaved siblings, which is when we achieved saturation, meaning that no new information came from the interviews. The characteristics of the participants are shown in table 1 and the characteristics of the deceased siblings are shown in table 2.

Table 3. Characteristics of the study participants

Participants' characteristics	**Number of participants (N=18)**
Gender	
Male	5
Female	13
Age at interview	
15 – 20	2
21 – 30	7
31 – 38	9
Residence at time of loss	
Rural community (<10,000 inhabitants)	3
Small town (<50,000 inhabitants)	5
Medium-size town (<200,000 inhabitants)	6
Big city (>200,000 inhabitants)	4
Occupation	
Professional	3
Skilled manual worker	4
Student	4
Maternity leave	3
Unemployed	4
Years since sibling's suicide at interview	
2 -5	9
6 -10	7
11 - 17	2

Table 4. Characteristics of the deceased siblings

Deceased siblings' characteristics	Number (N=18)
Gender	
Male	16
Female	2
Age at time of death	
15 – 20	2
21 – 30	14
31 – 38	2
Older/younger in relation to the bereaved sibling	
Older sibling	7
Younger sibling	11

4.4.2 Method and procedure

We chose to use a qualitative methodology since we considered it to be the most appropriate way to explore subjective experiences (Auerbach & Silvertein, 2003). Our goal was to investigate the subjective experiences that underlie professional help-seeking behavior in suicide-bereaved siblings. The aim was to increase our understanding of a) suicide-bereaved siblings' reported reasons for seeking or not seeking professional support, b) factors that determine their reported satisfaction or dissatisfaction when they received professional help, and c) suicide-bereaved siblings' experience-based recommendations to health providers. In this study *health services* was defined as the network of public and private providers of healthcare in Sweden including general practitioners, psychiatrists, psychologists, counselors, school nurses and social workers.

For data collection, we used narrative interviews (Jovchelovitch, S. & Bauer, M; 2000), which were not time-limited. The interviewer, intervened only when needed for clarification of some point in the participants' account. If the participant did not refer to professional help-seeking during the interview, the dialogue was directed along two questions:

a) Did you approach health services to ask for help?
The purpose of this question was to differentiate between the reasons why the participants had sought help or not from the health services and, in case they had received professional help, to find out what had made them satisfied or dissatisfied with the received professional help.
b) What would you recommend health services to do when encountering suicide-bereaved siblings in the future?

The purpose of this question was to get first hand recommendations to health professionals when encountering suicide-bereaved siblings. We wanted the participants to give their recommendations based on their own experience of seeking professional help.

4.4.3 Data analysis

After each interview, a secretary in our research group transcribed the recording verbatim. After checking the accuracy of the transcription we then proceeded with the qualitative analysis of the content, one interview at the time. For data analysis we were inspired by Graneheim and Lundman’s article regarding qualitative content analysis (Graneheim & Lundman, 2004), which includes the following steps:

a) Making verbatim transcripts of the recorded interviews.
b) Dividing the transcripts into meaning units.
c) Condensing meaning units while preserving the core.
d) Abstracting and labeling meaning units into codes.
e) Grouping all codes into sub-categories and categories.
f) Sorting categories into main themes

4.5 NATIONWIDE MAIN STUDY OF SUICIDE-BEREAVED PARENTS (STUDY III AND STUDY IV)

4.5.1 Identification of the study-population

Using the Swedish Cause of Death Register, we identified all persons (15-30 years old) who died by suicide (ICD-10, X60-X84: Intentional Self-Harm) between 2004 and 2007, that is to say 2 to 5 years before we contacted their parents. We were able to identify their parents by means of linkage of the Swedish Cause of death Register and the Multi-generation Register. The inclusion criteria for the bereaved parents were: to be born in one of the Nordic countries (Sweden, Norway, Denmark, Finland and Iceland), to be fluent in Swedish, and to have a registered address and a telephone number. We excluded parents who had lost more than one child. In addition, using the Swedish Population Register, we identified a random group of non-bereaved parents matched (1 non-bereaved to 2 suicide-bereaved) for age, gender, place of residence, marital status, number of children and having a child of the same age as the deceased child. The identification of the study-population, which followed the same inclusion criteria with the exception of having experienced the death of a child, and the matching with a non-bereaved group of parents were performed by the register holders to comply with the Swedish Law of Secrecy. We received the contact information for both groups of parents but we did not know who was bereaved and who was not. The parents in both groups disclosed this information themselves when we contacted them by telephone.

4.5.2 Participation

In total, 1423 parents were identified as eligible to participate in our study. Of these, 915 were suicide-bereaved and 508 were non-bereaved. We sent the introductory letter to these 1423 parents. We were able to contact 1410 of the 1423 eligible parents (99%). We started to collect the data in August 2009 and finished in December 2010, when the last questionnaire was returned to us. In total, we received answered questionnaires from 666 (73%) bereaved and 377 (74%) non-bereaved parents. Figure 10 shows the total number of bereaved and non-bereaved participants. Table 5 shows the description of non-participants.

Figure 10. Suicide-bereaved and non-bereaved participants

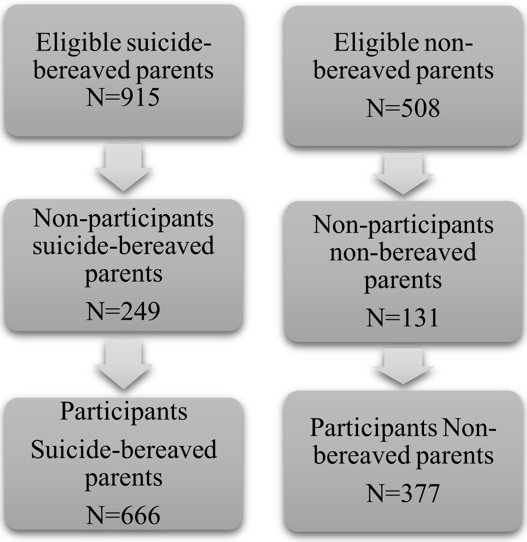


Table 5. Description of non-participants

	Non-participants suicide-bereaved N=249	Non-participants non-bereaved N=131
Non-reachable	N=8	N=5
Declined participation		
Distress or ill-health	N=19	N=7
No reason/other reasons	N=91	N=74
Partner declined	N=15	N=7
Agreed to participate withdrew		
Distress or ill-health	N=29	N=2
No reason/other reasons	N=76	N=27
Partner declined	N=4	N=1
Missing questionnaires	N=7	N=8

4.5.3 Timeframes used in studies III and IV

Regarding the timeframes, there are two aspects to be considered:

a) Our questionnaire collected data corresponding to different times. Some questions related to the time before the suicide (i.e. Did your child live together with you during the year before his/her death?), some to the time around the suicide (i.e. How did your child take his life?), and some to the time after the suicide (i.e. Have you had contact with a support group for bereaved people?). The questionnaire also includes questions about “today” referring to the last 2-4 weeks before filling in the questionnaire (for example, the psychometric scales PHQ-9 and GAD-2, to measure depression and anxiety, respectively).

b) The time since loss varies between the suicide-bereaved parents who participated in the study. Some of them had experienced 2 years of bereavement (N=161, 24%); others had been bereaved for three years (N=169, 25%), four years (N=174, 26%) or five years (N=162, 24%).

4.5.4 Psychometric scales (Study III and study IV)

In order to assess depression and anxiety in our study, we used two validated and officially translated (to Swedish) psychometric scales: the PHQ-9 and the GAD-2. The PHQ-9, is a module from the Patient Health Questionnaire (PHQ). It is a nine-item scale that can be used to diagnose major depressive disorder. The scores range from 0 to 27 and the cutoffs of 5, 10, 15, and 20 represent mild, moderate, moderately severe and severe levels of depressive symptoms, respectively (Kroenke, Spitzer, Williams, & Löwe, 2010). This scale has gained popularity to assess and monitor depression severity both in clinical practice and research settings since its performance is similar, whether self-administered or interviewer-administered, in person, by phone or computer (Fann et al., 2009). Also, the PHQ-9 is short, performs similarly across sex, age and racial groups (Kroenke et al., 2010).

To diagnose Generalized Anxiety Disorder, we used the GAD-2. This is a shortened version of the GAD-7, which is a 7-item validated scale that measures anxiety with similar response alternatives as the PHQ-9. The GAD-2 includes only two items, which correspond to the two core diagnostic criteria for Generalized Anxiety Disorder. Scores range from 0 to 6 and the cutoff of ≥3 stands for a screening point for clinically significant anxiety, which should be followed by further assessment (Kroenke et al., 2010).

In regard to our preparatory study (study I), where we tested our questionnaire for the bereaved parents, we decided to slightly change the response alternatives of these psychometric instruments in order to make them more similar to the answering format that we used for the other questions in the questionnaire. In this way, the response alternatives passed to be numerical and not verbal as in the original. For simplicity, we collated the GAD-2 right after the PHQ-9. To ease the understanding of questions 6 and 8 in the PHQ-9, which in the original version contain two conceptual entities in each each question, we divided each of these questions in two (see table 4).

Table 5. Patient Health Questionnaire – 9 (PHQ-9). P. Larsson Omerov. Parents who have lost a son or daughter through suicide – towards improved care and restored psychological health. Doctoral thesis. 2014

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
	Not at all	1–3 days a week	4–5 days a week	6-7 days a week
Red text=added text Blue text=removed text				
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).

4.5.5 Study III. Lack of trust in the healthcare services after losing a child to suicide

One of our study hypotheses was that suicide-bereaved parents present lower levels of trust in the healthcare system than non-bereaved parents. To answer this hypothesis we decided to include, in our study-specific questionnaire, a question concerning trust in the healthcare system.

4.5.6 Lack of trust in the healthcare system

We measured trust in the healthcare system in bereaved and non-bereaved parents using one question: *"Do you trust the Swedish healthcare system today?"* The response alternatives were: "No", "Yes, a little", "Yes, moderately" and "Yes, much". This question has been used in previous epidemiological studies of a Swedish population (Ahnquist et al., 2010). Then, we categorized the answers "No" and "Yes, a little" as *lack of trust is the healthcare services* and "Yes, moderately" and "Yes, much" as *trust in the healthcare services*. Figure 10 shows these questions, as they appeared in the questionnaires for bereaved and non-bereaved parents.

Figure 10. Study specific question to measure trust in the healthcare system in bereaved and non-bereaved parents.

Do you trust the Swedish healthcare system today?
- ☐ No
- ☐ Yes, a little
- ☐ Yes, moderately
- ☐ Yes, much

4.5.7 Psychological morbidity

In order to rule out previous *psychological morbidity* as a possible explanation for the differences in psychological outcomes that we could find between the bereaved and non-bereaved parents, we excluded the bereaved and non-bereaved parents who answered that they had suffered from psychological morbidity ten or more years before answering the questionnaire. Psychological morbidity was measured using four questions and sub-questions (Figure 11). These questions were identical for both groups of parents with the exception of the additional text "before my child's death" for the bereaved parents. Figure 11 shows these questions, as they appeared in the questionnaire while Figure 12 shows the timeline for measuring psychological morbidity. Bereaved and non-bereaved parents, who stated that they had suffered from psychological morbidity during the past 10 years, were included in the study, and those who presented psychological morbidity for more than 10 years were excluded.

Figure 11. Questions used to measure psychological morbidity (adapted from P. Larsson Omerov. Parents who have lost a son or daughter through suicide – towards improved care and restored psychological health. Doctoral thesis. 2014)

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 received medication against anxiety during some period of your life?
4) Have you received medication against low mood or depression during some period of your life?

* Non-bereaved parents only had the alternative "during the past 10 years"

Figure 12. Timeline for measuring psychological morbidity "more than 10 years earlier" and "during the last 10 years".

Psychological morbidity 10 or more years earlier	**Psychological morbidity during the past 10 years**										
					Offspring's suicide					**Receiving the Questionnaire**	
←1999*	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
Excluded parents	**Included parents**										

* Earliest year possible for presenting 10 or more years of psychological morbidity before receiving the questionnaire.

4.5.8 Other measures used in study III

In order to measure potential predictors of the outcome lack of trust in the healthcare services, we included current depression as measured by the PHQ-9, psychological morbidity during the last 10 years (both variables are described in detail above) and the following socio-demographic characteristics: gender, age, country of birth (Sweden or another Nordic country), residential area, educational level, source of income, yearly income, marital status, having remaining children and believing in God. We also used study-specific questions to assess physician-approved sick leave during the last year, social

activity, physical activity and loss of a parent to suicide. Furthermore, we asked the suicide-bereaved parents about their child's contact with psychiatric services, the year of the child's suicide and if they were
disappointed with the professional care the child received. These questions and their respective response alternatives are presented below in Table 5.

Table 5. Study-specific questions and their respective response alternatives used in this study

Have you been on sick leave (approved by a physician) during the last year?

- ☐ I have not worked during the last year
- ☐ No
- ☐ Yes

Have you practiced any physical activity during more than 30 minutes at one occasion during the last year? For example a fast walk

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

Have you met friends or acquaintances during the last year?

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

Did you lose a parent when you were 20 years old or younger?

- ☐ No
- ☐ Yes → If yes, did she or he take his life?
  - ☐ No
  - ☐ Yes

Questions addressed only to bereaved parents and included in this study:

Had your child ever had contact with the psychiatric services?

- ☐ I don't know
- ☐ No
- ☐ Yes

When did your child die? Year and month………………………………………………

Are you disappointed when you think about the care your son or daughter received?

- ☐ My child did not receive any care
- ☐ No
- ☐ Yes, a little
- ☐ Yes, moderately
- ☐ Yes, much

4.5.9 Statistical methods

Using log-binomial regression, we calculated the relative risks (95% confidence interval) of the outcome *Lack of trust in the healthcare system* in both bereaved and non-bereaved parents. Subsequently using Wilcoxon-Mann-Whitney's test we tested for trend across ordered categorical variables. Finally, taking only the bereaved group, we performed a multivariable modeling to assess which variables were more strongly associated with the outcome "Lack of trust in the healthcare services". This multivariable analysis was carried out using 100 complete data sets, through multiple imputations using the method called MICE – Multivariate Imputations by Chained Equations – in order to avoid problems related to non-response (Van Buuren & Groothuis-Oudshoorn, 2011). In each of the 100 data sets, we performed a separate logistic regression with forward selection using minimization of the Akaike Information Criterion as selection criterion. Variables that were present in the majority of datasets were then used for creating a final pooled logistic regression model (Wood, White, & Royston, 2008). We present the resulting multivariable odds ratios alongside the corresponding crude risk ratios and odds ratios derived from using the imputed data for comparison. We performed statistical tests at the 5% significance level. We used the MICE package in R (version 2.13.2, R Development Core Team, Vienna, Austria), and all other statistical analyses were done using SPSS (version 20, IBM Corp., Armonk, USA).

4.5.10 STUDY IV. CONFRONTING THE BODY AT THE SITE OF THE SUICIDE: A POPULATION-BASED SURVEY IN SWEDEN

One of the hypotheses that emerged from our preparatory study was that suicide-bereaved parents who confronted the body of their child at the site of the suicide are likely to have a higher prevalence of psychological distress compared to those who did not confront the body. For this reason, in this study we wanted to elucidate if, in the clinical context, more attention should be given to the parents that confront the body of their dead child at the site of death. For this purpose, we included in the questionnaire some questions in order to identify the psychological effects of confronting the child's body at the site of suicide. In this study, C*onfronting the body* was defined as finding the body of the child, witnessing the suicide or seeing the child immediately after someone else had found him/her.

4.5.11 Confronting the body of the dead child at the site of the suicide

Confronting the body of the dead child at the site of his/her suicide was the exposure variable. In order to discriminate which parents had confronted the body of their child and which parents had not, we used the question: *How did you find out that your child had died?* The parents that were categorized as having *"Confronted the body of the child"* where those who answered this question using one of the following response alternatives: "I was the one who found my child", "I saw my child at the site immediately after someone else found him/her", and those parents who marked the response alternative "In another way, namely" and wrote in the space for free-hand comments that they had witnessed the suicide of their child. The parents that were categorized as *"Not having confronted the body at the site of the* *suicide"* where those who answered that they had found out about the death of their child "*through a personal notification"* or "*through a notification by telephone*" (Table 7).

Table 7. Study-specific question to identify exposed parents

How did you find out that your child had died?

☐ I was the one who found my child
☐ I saw my child at the site immediately after someone else found him/her
☐ Through a personal notification
☐ Through a notification by telephone
☐ In written
☐ In another way --

4.5.12 Psychological effects of confronting the child's body at the site of the suicide

The outcome variables in this study were psychological effects of confronting the body of the dead child at the site of his/her suicide. In order to assess these variables, we measured the prevalence of nightmares, intrusive memories, avoidance of thoughts and avoidance of behaviors related to the offspring's suicide using four study-specific questions addressed only to the suicide-bereaved parents (Table 8). The response alternatives were dichotomized in No and Yes, were the answer "*No*" was categorized and No and the answers "*Yes, ocassionally*", "*Yes, 1-3 days a week*", "*Yes, 4-5 days a week*", and "*Yes, 6-7 days a week*" were categorized as Yes.

Table 8. Study-specific questions to measure the psychological effects of confronting the body at the site of the suicide. Response alternatives were the same for the four questions. Each question was followed by space for free comments.

1. 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

2. Have you relived your child's death through intrusive memories during the last month?

3. Have you avoided thinking about things that remind you about your child's death during the last month?

4. Have you avoided things that remind you about your child's death during the last month? For ex. places and things

4.5.13 Statistical methods

Using the recommended cutoff values for moderate to severe anxiety and depression, we dichotomized the summed scores of the PHQ-9 and GAD-2. Due to their easy interpretation, we decided to use log-binomial regression to show risk ratios. We also used odds ratios from logistic regression for multivariable adjustments. To identify the most important variables to adjust for, we performed an automated variable selection, logistic regression with forward selection, for each outcome using a liberal inclusion criterion ($p<0.15$) in order to avoid under-adjustment. Thereafter, we formed a final multivariable model for each outcome including the *confronting* variable in addition to the adjustment variables identified in this way. We performed statistical tests at the 5% significance level unless otherwise stated. Individuals with missing data were removed for each calculation. IBM SPSS Statistics (version 22, IBM Corp., Armonk, NY, USA) was used for all calculations.

5. ETHICAL CONSIDERATIONS

Suicide-bereaved relatives may be seen as a sensitive and vulnerable research population since they have experienced the horrible calamity that the suicide of a child or a sibling is. Due to this reason, ethical review boards may hesitate when pondering granting researchers permission to approach the bereaved and proceed with this kind of studies, on the grounds that participation may harm or re-traumatize the suicide-bereaved (Jorm, Kelly, & Morgan, 2007; Legerski & Bunnell, 2010). In our case, the research project of suicide-bereaved parents was denied ethical approval at first, and was delayed due to time-consuming, consecutive appealing before we received ethical approval from the Regional Ethics Committee.

5.1 ETHICAL CONSIDERATIONS IN OUR STUDY OF SUICIDE-BEREAVED PARENTS

When considering the ethical foundation of this project, we challenged the believes that asking suicide-bereaved individuals about their loss would harm them, “re-open old-wounds” and that negative effects of research participation will remain over time. During the planning phase of the study, we prepared an ethical protocol containing all the considerations that need to be taken into account throughout the research process in order to make the study ethically and methodologically sound (Table 9). Before proceeding, we also considered various ethical principles of medical research involving human participants (WHO, 2011). We assessed the *potential risks and benefits* of participation in our pilot study by asking the participants themselves if they though that they had been negatively affected by the survey and if they thought that this negative effect would remain. Furthermore, we made sure that any potential problem could be managed by sending only 50 questionnaires at a time. *Participation was voluntary* and we made it very easy for the participants to withdraw from the study. In our introductory letter, they were informed of their right to terminate their participation at any time without giving us an explanation. We also considered the principle of *confidentiality.*

Register holders made the identification of bereaved and non-bereaved parents. The parents, that wanted to participate, disclosed themselves their status when we contacted them by phone. Also*,* we made sure that all data were un-identifiable on an individual level. All parents, bereaved and non-bereaved were *informed* about the study in writing, and they received the contact information of the researchers to make it easy for them to ask questions. All the participants provided us their *consent* to take part in the study when we called them. Regarding, *conflicts of interest*, the researchers had no financial or other type of interest that could have biased the research findings and the founders had no part in the study design, data collection, analysis, or writing the manuscripts.

5.2 ETHICAL CONSIDERATIONS IN OUR STUDY OF SUICIDE BEREAVED SIBLINGS

The Regional Ethics Committee in Stockholm approved this qualitative study. Before the interviews, we assured the participants confidentiality and let them know of their right to stop or withdraw from the interview if they wished to do so. All of them gave their oral consent to participate in the study. After finishing each interview, the interviewer took some time to ask the participants how they were feeling, if there was something else they would like to say and gave them our contact information in case they wanted to talk further, had some questions or if they were feeling bad. From the 18 siblings who participated in the interviews, one of them contacted the interviewer because she had become aware that she needed psychological help. The main supervisor of this research project (an experienced psychiatrist and suicidologist) talked to this participant and referred her to a grief specialist. Months later, we received an email from her. In this email she thanked us for the help and told us that she was feeling better.

Table 9. Summary of the ethical considerations in our studies. Pernilla Larsson Omerov. Doctoral thesis (2013)

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
- Information 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 participants' 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, e.g. answering the questionnaire
- Ask for consent to call again during participation

6. RESULTS

6.1 STUDY I. PREPARATORY STUDIES TO A POPULATION-BASED SURVEY OF SUICIDE-BEREAVED PARENTS IN SWEDEN

6.1.1 Hypotheses, exposures and outcomes

The overall aim of our studies was to improve the professional care of suicide-bereaved families with a special focus on parents and siblings. We had various working hypotheses that we wanted to explore further with our questionnaire. The questions were formulated in a way to make it possible for us to measure possible exposures and outcomes. Some examples regarding how we transformed the hypotheses into study specific-questions are shown below in Table 10.

Table 10. Example of hypotheses turned into questions and their function in the statistical analysis.

Hypotheses	**Questions**	**Function in the statistical analysis**
Suicide-bereaved parents present higher prevalence of depression and anxiety than non-bereaved parents	PHQ-9 to measure depression and GAD-2 to measure anxiety	Outcome measures
Suicide-bereaved parents who consider that they were prepared for the suicide of their child present lower prevalence of depression and anxiety 2-5 years after their loss	Were you prepared for the suicide of your child when you found out that your child had died?	Exposure: Preparedness for the suicide of the child
Suicide-bereaved parents trust the health system to a lesser extent than non-bereaved parents	Do you trust the Swedish health system today?	*Exposure:* Bereaved – Non-bereaved. *Outcome:* Lack of trust in health system
Confronting the body of the deceased child at the suicide site increases the parents' prevalence of anxiety, depression and PTSD 2-5 years after their loss (See note *)	How did you find out that your child had died?	*Exposure*: Confronting the child's body at the site of death. *Outcome:* Prevalence of anxiety, depression and PTSD (See note *)
Suicide-bereaved parents do not regret participating in a survey regarding the suicide of their child	Do you regret your participation in the present study?	Outcome
Suicide-bereaved parents have lower levels of quality of life in comparison to non-bereaved parents	How has your quality of life been during the last month?	Outcome

* Note: In consideration to the length of the questionnaire, we decided not to use a psychometric scale to measure PTSD. Instead, we formulated some questions to measure symptoms related to PTSD and used these as outcomes.

6.1.2 The questionnaire

The validated questionnaire that we sent to suicide-bereaved parents consisted of 175 main questions, some of them followed by sub-questions and free-hand comments. We also created a questionnaire for the non-bereaved parents that contained the same questions except for the ones related to the loss (See Table 11).

Table 11. Areas of study covered in the questionnaire and examples of the questions used.

Areas covered by the questions	**Examples of questions**
Background (Questions 1-12)	- Are you a man or a woman? - Were you born in Sweden?
Psychological morbidity and quality of life. (Questions 13-40)	- PHQ-9 - How has your quality of life been during the last month?
The time before the son or daughter's death and trust in the healthcare services (Questions 41-64)	- Did your child live together with you before his/her death?
The death of the child and the immediate time after the death (Questions 65-106)	- How did your child take his/her life? - How did you find out that your child had died?
The time after the death of the child (Questions 107-119)	- Have you participated in a support group for suicide-bereaved? *Was it a positive experience?
Believe in God, grief and coping (Questions 120-141)	- Have you arranged a special memorial place at home? - Do you include the child you lost when you tell about the children that you have?
Own suicidality (Questions 142-145)	- Have you ever tried to take your own life? *Was it before or after your child's death?
Previous losses (Questions 146-150)	- Did you lose a parent when you were 20 years old or younger? *Was it by suicide? - Did you lose a sibling when you were growing up? *Was it by suicide?
Alcohol consumption. (Question 151)	- AUDIT (Alcohol Use Disorders Identification)
Contact with public authorities and employers (152-159)	- Have you been on sick-leave (approved by a doctor) during the last year? - Have you had contact with the Swedish Social Insurance Agency after the death of your child?
Place of residence, marital status, level of education and income (Questions 160-164)	- Which is your main source of income? - What is your marital status?
Physical and social activity (Questions 165-168)	- Have you practiced any physical activity during more than 30 minutes at one occasion during the last year? i.e. a fast walk. - Have you met friends or acquaintances during the last year? Response alternatives for these questions are: No. Yes, but not every month. Yes, at least once a month. Yes, at least once a week. Yes, every day.
Experience of participation (Questions 169-175)	- Do you consider that it is valuable to conduct a survey like this one? - Do you think this survey has had a positive effect on you? *Do you think this positive effect will remain on you?

* Sub-questions

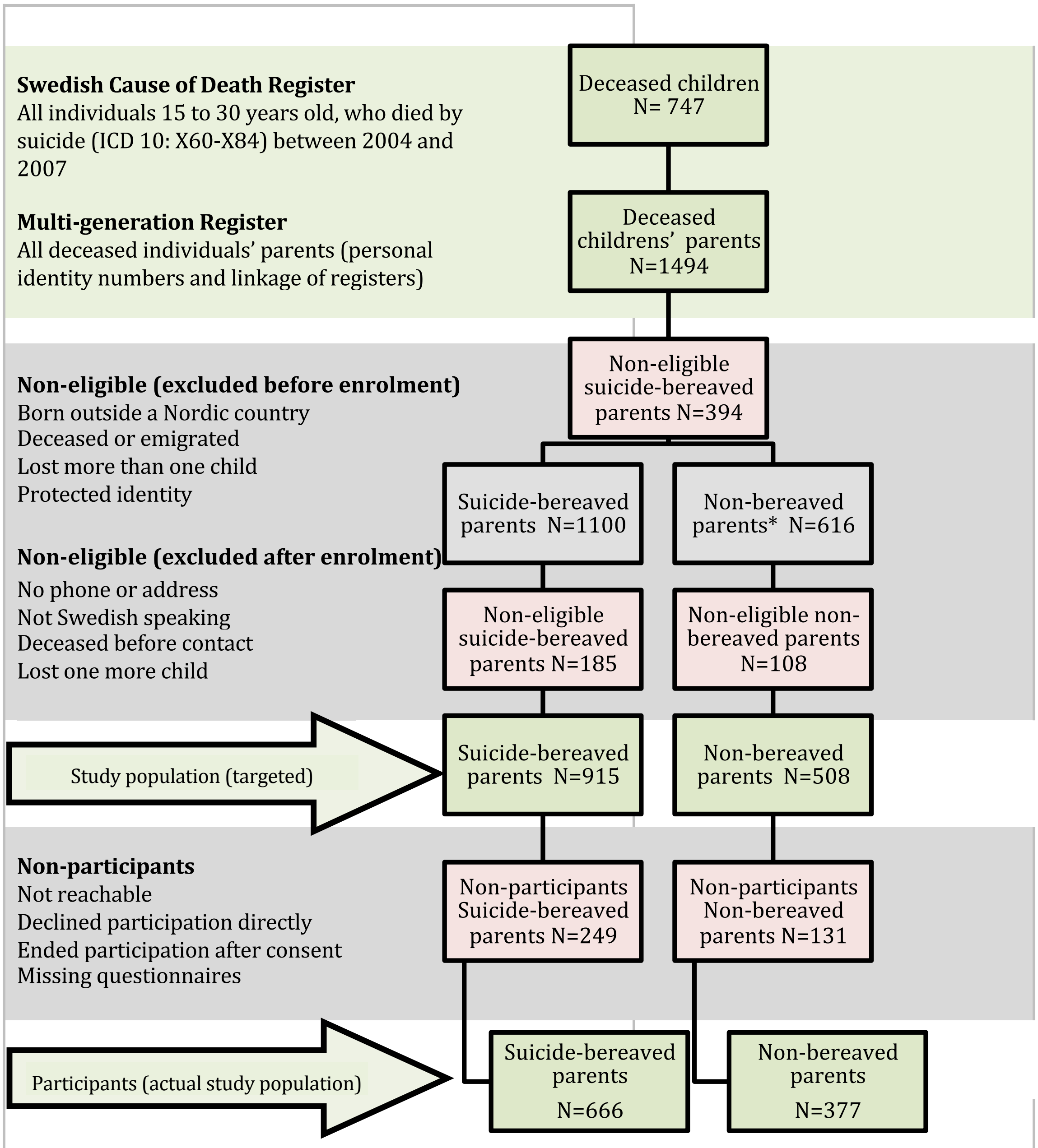
6.1.3 Conducting a pilot study

We performed the pilot study using a randomly selected sample of 79 parents (bereaved and non-bereaved) from the 1,426 that were identified as the study population. We contacted the 79 parents by phone to ask them if they were interested in seeing our questionnaire and participate in the study. Of these 79 parents, 65 (82%) agreed and 14 (18%) declined to participated. Of the 14 parents that declined participation, 7 did not give any reason for their decision, one husband said no on behalf of his wife, three parents stated that they never participated in surveys, two parents disagreed that the cause of their child's death was suicide, and one parent declined participation due to ill-health. Within a month, we received the answered questionnaires from 46 (58%) of all the parents that we approached, of whom 28 were bereaved and 18 were non-bereaved. Of the 46 parents that answered the questionnaire, 45 asserted that they found the survey valuable, 24 that they were positively affected and 3 asserted that they had been temporarily negatively affected by answering the questionnaire. However, most bereaved parents stated that they were mainly grateful for the opportunity to tell about their experience surrounding their child's death. The non-bereaved parents' comments were mainly about their appreciation for the new insights received while answering the questionnaire, like the value of having a child and that this child is healthy. The internal response rate of the questionnaire designed to be answered by the bereaved parents was 98% (range 82-100%) for the main questions. Based on these results and the fact that the bereaved parents appreciated being asked about their experience of losing a child by suicide, we decided to proceed with the main study.

6.1.4 Data collection for the main study

The collection of data started in August 2009 and finished in December 2010. In total, 1423 parents were identified as the targeted study population. This population consisted of 915 bereaved and 508 non-bereaved parents. The parents that actually participated in the study by returning their answered questionnaires consisted of 666 bereaved parents and a matched group of 377 non-bereaved parents which constituted the actual study population. For a complete account of participants and non participants, see Figure 13.

Figure 13. Participation and no-participation among suicide-bereaved and non-bereaved parents. Pernilla Larsson Omerov. Parents who have lost a son or daughter through suicide – towards improved care and restored psychological health. Doctoral thesis, 2014



* 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.

6.2 STUDY II. SUICIDE-BEREAVED SIBLINGS' PERCEPTION OF HEALTH SERVICES

The majority of participants (n=16) reported needing professional support after their sibling's suicide and most of them (n=11) actually sought professional help. The professional support that these siblings received ranged from a one-time meeting with a health professional in an emergency unit to various meetings with a psychologist, psychiatrist, school nurse or counselor. The findings of this study were obtained through the qualitative content analysis of 18 interviews with individuals who had lost a brother or a sister to suicide.

6.2.1 Reasons for seeking or not seeking professional help

Reasons for seeking professional help:

a) *To cope with grief responses*. This was the most frequent reason for seeking professional support. Bereaved siblings wanted help to cope with feelings of intense sadness after their loss, feelings of anger towards one-self or towards the deceased sibling and sleep difficulties such as nightmares and insomnia. Participants that were still attending school at the time of the sibling's suicide expressed that they also needed help with concentration difficulties during lessons, since this took a toll on their academic performance. Another reason was to cope with feelings of blame directed towards one-self. These siblings talked about "missing the signs" and told about repetitive thoughts around "why didn't I notice that my sibling was feeling bad?" Also, they mentioned that memories became very fragmentary after the loss of the sibling. When recalling their life before the sister's or brother's suicide , the sad moments took a bigger place and the happy memories were hard to retrieve.

b) *To facilitate social relationships*. Participants referred to their need of professional help to facilitate the relationships with other persons. One female participant expressed her need of professional help to stop engaging in romantic relationships with men who had psychological problems. She had been in dysfunctional relationships since the suicide of her brother. Other participants wanted to contact a health professional because they thought that it was difficult to talk about their problems with family members since they were also sad. They wanted to talk to someone who would be objective and with whom they could openly express their sadness. In this way, they would not need to "carry these feelings" with them at home or at work.

c) *To search for reasons leading to sibling's suicide*. A couple of participants sought contact with the professional who had been treating the deceased sibling. They wanted the professional to explain the reasons for the sibling's suicide. Being able to meet the treating professional and hospital managers was appreciated by one of these siblings. Despite the fact that he still held the involved professionals accountable for the sibling's suicide, he appreciated the opportunity given to the bereaved family to ask questions, vent their anger and sadness, and to receive the offer of psychological support. The other participant was disappointed that the treating professional was unavailable each time she had tried to contact him.

Other participants (7/18) did not seek professional help. The reasons for not seeking professional help formed three main themes:

a) *Lack of trust in the healthcare services' availability to help.* After seeing that the bereaved sibling repetitively sought professional help and did not receive it, or that he or she received it but it was insufficient, some bereaved siblings assumed that professional help would not be available for them either. They mentioned that necessary conditions for seeking professional help are the actual availability of help and being encountered by professionals who unequivocally want to help them.

b) *Overwhelming grief.* Another reason why bereaved siblings did not seek professional help was feeling so overwhelmed and affected by their grief that they did not have the mental or physical strength to ask for help. They perceived that one needs to make multiple telephone calls and insist repetitively to be able to receive psychological support. They also described intense grief that drained them of the mental strength to be on waiting list for treatment. They asserted that this state of mind became a downward spyral where the worst they felt, the less strength they had and the more help they needed. Considering their overwhelming grief, some participants thought that the health system should reach out and actively contact the bereaved families with the offer of professional support.

c) *No experienced need of help from health services*. Two participants reported that they did not need professional help since they received all the help they needed from close friends, family members or other suicide-bereaved persons. They stated that persons who knew the deceased sibling and persons who have gone trough the same experience were better able to understand and provide them with the help they needed in an empathic and supporting way.

6.2.2 Assessment of the help received from health services

Reasons for satisfaction with the received professional help fell into three main themes:

a) *Receiving grief-related support*. Participants reported to be satisfied with the professional help they received when professionals helped them to cope with feelings of guilt, concentration problems at school, referred them to grief specialists, and when they provided the bereaved siblings with information of various sources of help such as support groups and helplines. In their search for reasons for the sibling's suicide, participants also appreciated when professionals explained the possible causes for the suicide and how depression affects individuals.

b) *Empathic encounter*. Participants reported to have been satisfied with the received professional help when they perceived that they had been encountered in an empathic way, without the professional making them feel pitied. These empathic encounters included verbal and non-verbal affirmations such as keeping eye contact, listening attentively and acknowledging the difficult situation of the bereaved sibling without belittling them.

c) *Psychosocial benefits*. Other reasons for satisfaction with the received professional help was when the bereaved siblings experienced psychosocial benefits from the professional intervention. They reported that they did not want to burden family members and friends with their feelings of sadness and grief-related difficulties. In this sense, therapy was the place where they could pour all their feelings and this reduced their need to share the feelings with their loved-ones.

Reasons for dissatisfaction with the received professional help fell into four main themes:

a) *Lengthy access*. Bereaved siblings reported dissatisfaction and frustration when receiving professional support implied a lengthy process and difficulties to receive psychological help and follow-up sessions within the public healthcare system. They said that seeking professional support from a private provider was an expensive and therefore often impossible alternative. In this regard, the participants spontaneously referred to the difficulties that their deceased sibling had experienced in order to get professional help. These participants assumed that the deceased sibling had died as a consequence of not receiving professional help when needed due to the tediousness of the help-seeking process.

b) *Insufficient care.* Some participants expressed dissatisfaction with the received professional help when they considered it as insufficient due to too few sessions or when the professional intervention consisted only on the prescription of psychotropics but did not include psychotherapy as well.

c) *Non-empathic encounter*. Another source of dissatisfaction with the professional help received was the perceived lack of empathy from health professionals. The bereaved siblings complained about the too short duration of first-time consultations, the professionals not building rapport with the bereaved and not showing authentic concern and seeming to be insecure about what to say to the bereaved. When describing the lack of empathy from health professionals, the bereaved siblings spontaneously referred to the lack of empathy that they perceived that their deceased sibling had experience from health professionals.

d) *Perceived professional incompetence*. A reason for dissatisfaction with help from professionals, and also a reason for discontinuing therapy, was when the bereaved siblings perceived the professional as incompetent or unqualified. The perception of incompetence was related to insufficient communication with the bereaved sibling and lack of understanding of their immense pain. Professionals were considered incompetent when they were too quiet, did not engage in a dialogue with the bereaved, and when the professional immediately suggested medication without really listening. Some bereaved siblings also told about professionals who were nice to talk to but that did not capture nor helped them with their bereavement related needs and difficulties. While talking about the perceived incompetence of health professionals, some bereaved siblings spontaneously referred to the experience of their deceased sibling in this respect. They considered that the health professionals thathad treated the deceased sibling were incompetent since they had failed to notice the suicide risk, had provided only restrictive or pharmacological interventions without providing psychotherapeutic treatment. Probing further into the bereaved siblings' perception of pharmacological treatment, some of them said that they had being prescribed medication due to severe symptoms of anxiety and depression but that they had refused to take the medication. As reasons for this behavior, they mentioned their lack of trust in psychiatrists to prescribe the "right medication" since they believed that their deceased sibling had died due to receiving the "wrong medication."

6.2.3 Experience-based recommendations to health professionals when meeting suicide-bereaved siblings

The bereaved siblings' recommendations to health professionals fell into three main themes:

a) *Immediate and repeated contact.* The most frequent theme in the bereaved siblings' recommendations to health professionals was that the healthcare services ought to systematically contact the bereaved siblings with the offer of help. The offer of help should be provided regardless of the bereaved asking for it or not since the suicide of a sibling leaves the bereaved in a psychological condition where they 1) Do not have the emotional strength to seek for professional support themselves, 2) If seeking for professional help, the bereaved siblings do not always know how to explain what they need and 3) Being contacted by the health services would signify the acknowledgement of their grief and need of help.

They wanted the offer of help to be immediate after the suicide of the sibling and that it should be repeated in time more than once, because some bereaved siblings may not be prepared to receive professional help right after their loss, but that they would accept it later, when the shock has lessened. The funeral of the sibling was seen as a demarcation point. Many of the bereaved siblings received support from their family, friends and other netweorks until that point, but after the funeral the support from others diminished leaving the surviving siblings feeling lonely and in need of help.

b) Empathic and personal meetings with the bereaved. Most participants stressed that health professionals should be very empathic and respectful when meeting suicide-bereaved siblings. They considered certain behaviors as disrespectful. For example, misnaming the deceased, not looking the bereaved into their eyes, and recommending books with titles like “Stop complaining and move on” or when crises teams visited the bereaved family to offer support and sent the invoice the day after.

c) *Provision of information and grief-related support.* Participants recommended health professionals to provide suicide-bereaved siblings with practical and specific information. Practical information was suggested to include a package containing the contact details of different sources of help like health care centers, mental health units, support groups and grief specialist as well as information regarding how to apply for sick leave and information about common causes of suicide. The bereaved-siblings also recommended health professionals to give specific information such as current research on suicide prevention, which they said would be regarded as a hope-generating gesture towards a better treatment of suicidal patients. If the deceased sibling had been under treatment, the bereaved siblings recommended health professionals to be available to talk to the bereaved relatives and provide information about what the presumptive reasons for the sibling’s suicide. For some participants, the fear of suicide and mental ill-health in their children were sources of distress, even if they were childless at the timeof the interview. They recommended professionals to openly talk to them about the likelihood of mental illness and suicides in their family.

Participants also recommended health professionals to provide grief-related support to suicide-bereaved siblings. In this respect, some of them experienced constant worry and feelings of an approaching disaster. They reported anxiety when a loved one did not answer the phone or took longer than expected to come home and wanted professionals to specifically investigate such symptoms in bereaved siblings and help them to cope with them. Also, some participants had small children or were pregnant at the time of the sibling’s suicide. Others became parents some years later. They had felt a need of professional help concerning how to disclose the cause of the sibling’s death to their children. Two women reported the resurgence of grief feelings when having a newborn, years after the loss. These feelings consisted in perceiving the absence of the deceased sibling in an additional dimension, meaning that the newborn will never be able to meet his/her aunt/uncle. They also described painful thoughts concerning their own ability to be good mothers “having gone through this experience.” Those participants whose parents were divorced at the time of the loss, recommended health professionals to pay special attention to this group. They reported experiencing additional stress arising from the need to support both parents, each of them living in their own household. This additional burden deprived the bereaved siblings from the needed time and strength to share their own feelings with remaining siblings.

6.2.4 Influence of the deceased sibling’s experience with health services on the bereaved sibling’s perception of health services

We observed that the deceased sibling’s experience with the health services became a point of reference that influenced the bereaved sibling’s perception of the health services. When the bereaved sibling considered his/her encounter with health services as positive, meaning that his/her needs had been met, they did not make any reference to the deceased sibling’s experience with health services, whether positive or negative. On the contrary, when the bereaved sibling considered that his/her experience with health services as negative, meaning that his/her needs had not been met by health professionals, they made instant reference to the negative experiences of the deceased sibling with health services, mentioning everyway in which the deceased sibling’s needs had not been addressed by the health services (Table 12).

Table 12. Cross-table showing the emphasis laid on negative experiences in the narrative of the bereaved siblings when referring to deceased sibling’s experience with health services

		Deceased sibling	
	Experience when seeking help from health services	Positive experience (needs were met)	Negative experience (unmet needs)
Bereaved sibling	Positive experience (needs were met)	Not mentioned	
	Negative experience (unmet needs)	Not mentioned	**Emphasized**

6.3 STUDY III. LACK OF TRUST IN THE HEALTHCARE SYSTEM AFTER LOSING A CHILD TO SUICIDE: A NATIONWIDE POPULATION SURVEY

The original study population consisted of 666 suicide-bereaved and 377 non-bereaved parents. After excluding the bereaved and non-bereaved parents who reported psychological morbidity for 10 or more years before receiving our questionnaire, 569 suicide-bereaved and 326 non-bereaved parents were included. Below, in table 13, we present the participants’ characteristics, which were generally similar between bereaved and non-bereaved.

Table 13. Participants' characteristics

Participants' characteristics	Suicide-bereaved [1]	Non-bereaved [2]
Total providing information	569	326
Sex		
Male	254 (44.6)	150 (46.0)
Female	315 (55.4)	176 (54.0)
Age		
40 - 49	76 (13.4)	48 (14.7)
50 - 59	336 (59.1)	177 (54.3)
60 - 64	113 (19.9)	69 (21.2)
65 - 81	44 (7.7)	32 (9.8)
Year of child's death		
2004	132 (23.2)	Not applicable
2005	150 (26.4)	-
2006	149 (26.2)	-
2007	138 (24.3)	-
Age of deceased child		
15 - 19	122 (21.4)	Not applicable
20 - 24	224 (39.4)	-
25 - 31	223 (39.2)	-
Sex of deceased child		
Male	392 (68.9)	Not applicable
Female	177 (31.1)	-
Country of birth		
Sweden	537 (94.4)	323 (99.1)
Other Nordic country	32 (5.6)	3 (0.9)
Residential area		
Rural	142 (25.0)	67 (20.6)
Village <10 000	133 (23.4)	86 (26.4)
Small town <50 000	110 (19.3)	64 (19.6)
Town <200 000	95 (16.7)	49 (15.0)
City > 200 000	81 (14.2)	60 (18.4)
Not stated	8 (1.4)	0 (0)
Level of education		
Elementary school or less	123 (21.9)	63 (19.3)
Junior college	244 (43.4)	135 (41.4)
College or university (<3 years)	58 (10.3)	48 (14.7)
College or university (>3 years)	137 (24.4)	80 (24.5)
Not stated	7 (1.3)	0 (0)
Source of income		
Employed/Self-employed	444 (78.9)	264 (81.0)
Old-age pension	45 (8.0)	36 (11.0)
Disability pension	37 (6.6)	12 (3.7)
Social security	2 (0.4)	0 (0)
Unemployment fund	23 (4.1)	5 (1.5)
Study allowance	4 (0.7)	0 (0)
Other (house wife, passive income, etc.)	8 (1.4)	9 (2.8)
Not stated	6 (1.1)	0 (0)
Yearly income (SEK)		
0 – 99 000	28 (4.9)	8 (2.5)
100 000 – 199 000	85 (14.9)	53 (16.3)
200 000 – 399 000	339 (59.6)	207 (63.5)
400 000 or more	103 (18.1)	54 (16.6)
Not stated	14 (2.5)	4 (1.2)
Marital status		
Living with partner	421 (74.0)	235 (72.1)

Partner but lives alone	35 (6.2)	24 (7.4)
Single	91 (16.0)	57 (17.5)
Widow/widower	17 (3.0)	10 (3.1)
Not stated	5 (0.9)	0 (0)
Physician approved sick-leave last year		
Unemployed	37 (6.5)	23 (7.1)
No	426 (74.9)	252 (77.3)
Yes	99 (17.4)	48 (14.7)
Not stated	7 (1.2)	3 (0.9)
Physical activity		
Less than once a week	116 (20.4)	61 (18.7)
At least once a week	440 (77.3)	264 (81.0)
Not stated	13 (2.3)	1 (0.3)
Social activity		
Less than once a week	186 (33.5)	69 (21.3)
At least once a week	369 (66.5)	255 (78.7)
Not stated	14 (2.4)	2 (0.6)
Lost a parent to suicide		
No	547 (97.3)	320 (99.1)
Yes	15 (2.7)	3 (0.9)
Not stated	7 (1.2)	3 (0.9)
Belief in God		
No	314 (55.2)	189 (58.0)
Yes	233 (40.9)	129 (39.6)
Not stated	22 (3.9)	8 (2.5)

[1] Parents that lost a child aged 15-30 to suicide in Sweden between 2004-2007. [2] Random sample of non-bereaved parents from the Swedish population register matched to the suicide-bereaved parents for age, sex, place of residence and having a living child of the same age as the deceased child.

6.3.1 Lack of trust in the healthcare system

From the 569 bereaved and 326 non-bereaved parents who participated in this study, 544 (96%) bereaved and 323 (99%) non-bereaved parents answered the question regarding lack of trust in the healthcare system. We found that this outcome was more prevalent among the suicide-bereaved parents (47%) compared to the non-bereaved parents (18%), resulting in a Relative Risk (RR) of 2.5 (95% CI 2.0 – 3.3). There was a gender difference. Among the bereaved parents, the females presented more lack of trust (49.8%) when compared to males (42.4%). Among the non-bereaved parents, females (19%) were also slightly more distrustful than males (17.4%). Regarding age, among the bereaved parents,the group aged 60-64 years presented the highest lack of trust (50%) in the healthcare system, while in the non-bereaved parents, the youngest group, conformed by those parents aged 40-49 years, presented the highest lack of trust (31%).

After performing a test for trend across the variables that we considered as possible predictors of the outcome lack of trust in the healthcare system, we observed a statistically significant trend ($p<0.001$) for residential area in the bereaved parents. Lack of trust increased with population size. Bereaved parents living in big cities (>200,000 inhabitants) presented the highest prevalence of lack of trust. In contrast, we found no significant trend with respect to lack of trust and place of residence in non-bereaved parents. In the analysis of trend, we also observed a statistically significant trend (p=0.012) in the bereaved parents according to level of education. Bereaved parents with higher levels of education – college or university – presented greater lack of trust in the healthcare system than bereaved parents with lower levels of education. In contrast, we did not observe a trend in the non-bereaved parents in relation to level of education. However, lack of trust was more prevalent in those with lower educational achievement among the non-bereaved. Another statistically significant trend observed in this analysis was the one regarding lack of trust in the healthcare system and self-assessed depression. This significant trend was observed both in the bereaved (p<0.001) and non-bereaved (p=0.001) parents, where lack of trust in the healthcare system increased according to depression scores (Table 14).

Table 14. Test for trend across possible predictors of lack of trust in suicide-bereaved and non-bereaved parents

	Lack of trust in health system					
	Bereaved parents			Non-bereaved parents		
	n/N (%)	RR	Test for trend p-value	n/N (%)	RR	Test for trend p-value
Total	253/544 (46.5)			59/323 (18.3)		
Predictors						
Gender			Not applicable			Not applicable
Male	103/243 (42.4)	0.9 (0.7 - 1.0)		26/149 (17.4)	0.9 (0.6 - 1.5)	
Female	150/301 (49.8)	1.0 [reference]		33/174 (19.0)	1.0 [reference]	
Age			0.639			0.042*
40-49	32/73 (43.8)	1.0 [reference]		15/48 (31.2)	1.0 [reference]	
50-59	148/319 (46.4)	1.1 (0.8 - 1.4)		30/175 (17.1)	0.5 (0.3 - 0.9)	
60-64	55/110 (50.0)	1.1 (0.8 - 1.6)		8/69 (11.6)	0.4 (0.2 - 0.8)	
65-81	18/42 (42.9)	1.0 (0.6 - 1.5)		6/31 (19.4)	0.6 (0.3 - 1.4)	
Year of child's death			0.306			Not applicable
2004	60/126 (47.6)	1.0 [reference]		Not applicable	Not applicable	
2005	62/147 (42.2)	0.9 (0.7 - 1.2)		-	-	
2006	62/143 (43.4)	0.9 (0.7 - 1.2)		-	-	
2007	69/128 (53.9)	1.1 (0.9 - 1.4)		-	-	
Country of birth			Not applicable			Not applicable
Sweden	238/515 (46.2)	1.0 [reference]		58/320 (18.1)	1.0 [reference]	
Other Nordic country	15/29 (51.7)	1.1 (0.8 - 1.6)		1/3 (33.3)	1.8 (0.4 - 9.3)	
Residential area			<0.001*			0.570
Countryside	52/136 (38.2)	1.0 [reference]		12/67 (17.9)	1.0 [reference]	
Village <10 000	49/121 (40.5)	1.1 (0.8 - 1.4)		13/86 (15.1)	0.8 (0.4 - 1.7)	

Small town < 50 000	50/107 (46.7)	1.2 (0.9 - 1.6)		15/62 (24.2)	1.4 (0.7 - 2.7)	
Town <200 000	51/92 (55.4)	1.5 (1.1 - 1.9)		5/48 (10.4)	0.6 (0.2 - 1.5)	
City >200 000	47/80 (58.8)	1.5 (1.2 - 2.0)		14/60 (23.3)	1.3 (0.7 - 2.6)	
Level of education			0.012*			0.190
Elementary school or less	45/120 (37.5)	0.7 (0.5 - 0.9)		13/63 (20.6)	1.5 (0.7 - 3.0)	
Junior college	109/233 (46.8)	0.9 (0.7 - 1.1)		28/134 (20.9)	1.5 (0.8 - 2.8)	
College or university (<3 years)	29/55 (52.7)	1.0 (0.7 - 1.3)		7/48 (14.6)	1.0 (0.4 - 2.5)	
College or university (>3 years)	68/129 (52.7)	1.0 [reference]		11/78 (14.1)	1.0 [reference]	
Source of income			Not applicable			Not applicable
Employed/self-employed, study allowance	199/426 (46.7)	1.0 [reference]		42/262 (16.0)	1.0 [reference]	
Old-age pension	17/42 (40.5)	0.9 (0.6 - 1.3)		7/36 (19.4)	1.2 (0.6 - 2.5)	
Disability pension, unemployment, social security, other	35/70 (50.0)	1.1 (0.8 - 1.4)		10/25 (40.0)	2.5 (1.4 - 4.3)	
Yearly income SEK			0.441			0.109
0 - 199,000	47/112 (42.0)	1.0 [reference]		14/61 (23.0)	1.0 [reference]	
200,000 - 399,000	153/320 (47.8)	1.1 (0.9 - 1.5)		37/205 (18.0)	0.8 (0.5 - 1.4)	
400,000 or more	46/98 (46.9)	1.1 (0.8 - 1.5)		6/53 (11.3)	0.5 (0.2 - 1.2)	
Marital status			Not applicable			Not applicable
Living with a partner	169/398 (42.5)	1.0 [reference]		36/233 (15.5)	1.0 [reference]	
Partner but lives alone	19/34 (55.9)	1.3 (1.0 - 1.8)		6/24 (25.0)	1.6 (0.8 - 3.4)	
Single	56/90 (62.2)	1.5 (1.2 – 1.8)		16/57 (28.1)	1.8 (1.1 – 3.0)	
Widow/widower	7/17 (41.2)	1.0 (0.5 - 1.7)		1/9 (11.1)	0.7 (0.1 – 4.7)	
Physician approved sick leave last year			Not applicable			Not applicable
Unemployed	15/37 (40.5)	0.9 (0.6 - 1.3)		5/23 (21.7)	1.2 (0.5 - 2.6)	

No	189/404 (46.6)	1.0 [reference]		47/251 (18.7)	1.0 [reference]	
Yes	47/97 (48.5)	1.0 (0.8 - 1.3)		5/47 (10.6)	0.6 (0.2 - 1.4)	
Physical activity			Not applicable			Not applicable
Less than once a week	54/111 (48.6)	1.1 (0.8 - 1.3)		12/61 (19.7)	1.1 (0.6 - 2.0)	
At least once a week	195/421 (46.3)	1.0 [reference]		47/262 (16.9)	1.0 [reference]	
Social activity			Not applicable			Not applicable
Less than once a week	87/174 (50.0)	1.1 (0.9 - 1.3)		10/67 (14.9)	0.8 (0.4 - 1.5)	
At least once a week	162/357 (45.4)	1.0 [reference]		49/255 (19.2)	1.0 [reference]	
Lost a parent to suicide			Not applicable			Not applicable
No	246/523 (47.0)	1.0 [reference]		58/317 (18.3)	1.0 [ref]	
Yes	5/14 (35.7)	0.8 (0.4 - 1.5)		1/3 (33.3)	1.8 (0.4 - 9.2)	
Believe in God			Not applicable			Not applicable
No	140/300 (46.7)	1.0 [reference]		41/188 (21.8)	1.0 [ref]	
Yes	106/227 (46.7)	1.0 (0.8 - 1.2)		15/128 (11.7)	0.5 (0.3 - 0.9)	
Depression PHQ-9			<0.001*			<0.001*
0 - 4	115/287 (40.1)	1.0 [reference]		39/262 (14.9)	1.0 [ref]	
5 - 9	86/171 (50.3)	1.3 (1.0 - 1.5)		12/37 (32.4)	2.2 (1.3 - 3.8)	
10 - 14	28/47 (59.6)	1.5 (1.1 – 2.0)		7/18 (38.9)	2.6 (1.4 - 5.0)	
15 - 19	16/25 (64.0)	1.6 (1.2 - 2.2)		1/3 (33.3)	2.2 (0.4 - 11.4)	
20 - 27	4/6 (66.7)	1.7 (0.9 - 3.0)		0/0 (-)	-	
Psychiatric morbidity last 10 years*			Not applicable			Not applicable
During last 10 years	105/213 (49.3)	1.1 (0.9 - 1.3)		11/49 (22.4%)	1.3 (0.7 - 2.3)	
Never	148/331 (44.7)	1.0 [reference]		48/274 (17.5%)	1.0 [ref]	
Having remaining children			Not applicable			Not applicable
No	15/34 (44.1)	0.9 (0.6 - 1.4)		Not applicable	Not applicable	
Yes	238/510 (46.7)	1.0 [reference]		Not applicable	Not applicable	

* p-value < 0.05

In the multivariable analysis only bereaved parents were included. After performing a multivariable modeling through a stepwise forward selection, we identified three variables as associated with the outcome lack of trust in the healthcare system: Depression as measured by the PHQ-9, residential area and marital status (table 15).

Table 15. Multivariable analysis.

Selected variables[1]	Crude RR (95%CI)	Crude OR (95%CI)	Multivariable OR[2] (95% CI)
Depression score PHQ-9			
0 - 4	1.0 [reference]	1.0 [reference]	1.0 [reference]
5 - 9	1.3 (1.0 - 1.6)	1.5 (1.1 - 2.3)	1.5 (1.0 - 2.2)
10 - 14	1.5 (1.1 – 2.0)	2.2 (1.2 - 4.1)	2.1 (1.1 - 4.1)
15 - 19	1.6 (1.2 - 2.2)	2.8 (1.2 - 6.4)	2.6 (1.1 - 6.1)
20 - 27	1.7 (0.9 - 3.0)	3.0 (0.5 - 16.8)	2.4 (0.4 - 14.3)
Residential area			
Countryside	1.0 [reference]	1.0 [reference]	1.0 [reference]
Village <10 000	1.1 (0.8 - 1.4)	1.1 (0.7 - 1.8)	1.1 (0.6 - 1.8)
Small town < 50 000	1.2 (0.9 - 1.6)	1.4 (0.9 - 2.4)	1.3 (0.8 - 2.3)
Town <200 000	1.5 (1.1 - 1.9)	2.1 (1.2 - 3.5)	1.9 (1.1 - 3.3)
City >200 000	1.5 (1.2 - 2.1)	2.3 (1.3 - 4.1)	2.2 (1.3 - 4.0)
Marital status			
Living with a partner	1.0 [reference]	1.0 [reference]	1.0 [reference]
Partner but lives alone	1.3 (1.0 - 1.8)	1.7 (0.9 - 3.5)	1.6 (0.8 - 3.3)
Single	1.5 (1.2 – 1.8)	2.2 (1.4 - 3.6)	1.9 (1.2 – 3.1)
Widow/widower	1.0 (0.5 - 1.7)	1.0 (0.4 – 2.6)	0.9 (0.3 -2.5)

[1] Variables were selected using logistic regression with forward selection. Three variables were statistically significantly associated with lack of trust. Variables included in the selection were: gender, age, year of child's death, country of birth, residential area, level of education, source of income, yearly income, marital status, physician approved sick leave during last year, physical activity, social activity, lost a parent to suicide, believe in God, depression PHQ-9, psychiatric morbidity last 10 years, having remaining children. [2] ORs were adjusted for the selected variables

6.3.2 Disappointment with the health care provided to one's child

Among the bereaved parents who reported moderate to much disappointment with their child's healthcare, 161/227 (71%) reported lack of trust in the healthcare system today as compared to 20/96 (21%) who reported no or little disappointment and 71/217 (33%) of those parents who reported that their child had not received healthcare (Table 16).

Table 16. Percentage of lack of trust in the healthcare system according to degree of disappointment with the healthcare provided to own child

Disappointment	Parents reporting lack of trust in healthcare system
Moderate-Much disappointment	161/227 (71%)
No-Little disappointment	20/96 (21%)
Child did not receive health care	71/217 (33%)

6.4 STUDY IV. CONFRONTING THE BODY AT THE SITE OF THE SUICIDE: A POPULATION-BASED SURVEY IN SWEDEN

From the 915 eligible suicide-bereaved parents, 666 (73%) answered and returned the questionnaire to us. The question "How did you find out that your child had died?" was answered by 659 (99%) of the 666 participants. Of the 659 suicide-bereaved parents that answered the question regarding the circumstances related to confronting the body of the deceased child, 147 (22%) reported that they had confronted the body of their dead child at the death scene and 512 (58%) reported that they had not confronted the body of their dead child. The sociodemographic characteristics of the participants that had confronted and those who had not confronted the body of their deceased child were generally similarly distributed. These are shown in Table 17.

Table 17. Sociodemographic characteristics	**Suicide-bereaved parents**		
	Confronted body at the site of death*	Did not confront the body at the site of death	p-value
Sex – no. (%)			0·885†
Fathers	63/147 (43)	216/512 (42)	
Mothers	84/147 (57)	296/512 (58)	
Age – yr			
Fathers, Median (IQR)	59 (54-62)	57 (53-62)	0·213‡
Mothers, Median (IQR)	56 (52-60)	55 (50-59)	0·233‡
Year of child's death – no. (%)			0·268†
2004	35/147 (24)	125/512 (24)	
2005	38/147 (26)	134/512 (26)	
2006	45/147 (31)	121/512 (24)	
2007	29/147 (20)	132/512 (26)	
Age deceased child – yr Median (IQR)	22 (19-26)	23 (20-27)	0·094‡
Sex deceased child – no. (%)			0·093†
Male	110/147 (75)	346/512 (68)	
Female	37/147 (25)	166/512 (32)	
Children – no. (%)			
No remaining children	9/147 (6)	37/512 (7)	0·643†
Remaining children	138/147 (94)	475/512 (93)	
Biological child – no. (%)			
Non biological child	14/147 (10)	17/512 (3)	0·002†
Biological child	133/147 (90)	495/512 (97)	
Family constellation at time of death – no. (%)			0·073†
Living with a partner	119/147 (81)	376/510 (74)	
Not living with a partner	28/147 (19)	134/510 (26)	
Family constellation at time of study			0·075†
Living with a partner	111/145 (77)	363/509 (71)	
Single	28/145 (19)	90/509 (18)	
Has a partner but lives alone	3/145(2)	41/509 (8)	
Widow/widower	3/145 (2)	15/509 (3)	
Residence area at time of study – no. (%)			0.624†
Rural	39/144 (27)	121/507 (24)	
Village (population less than 10,000)	38/144 (26)	114/507 (22)	
Small town (population less than 50,000)	27/144 (19)	101/507 (20)	
Town (population less than 200,000)	21/144 (15)	95/507 (19)	
Larger town (population more than 200,000)	19/144 (13)	76/507 (15)	
Country of birth – no. (%)			0·224†
Born in Sweden	136/147 (93)	486/511 (95)	
Born in other Nordic country	11/147 (7)	25/511 (5)	
Level of education – no. (%)			0·723†
Less than elementary school	2/145 (1)	3/508 (<1)	
Elementary school	27/145 (19)	114/508 (22)	
Junior college	59/145 (41)	209/508 (41)	
College or university (< 3 years)	19/145 (13)	62/508 (12)	
College or university (≥ 3 years)	38/145 (26)	120/508 (24)	
Source of income – no. (%)			0·535†
Employed or self-employed	109/145 (75)	385/508 (76)	
Old-age pension	11/145 (8)	47/508 (9)	
Disability pension	18/145 (12)	42/508 (8)	
Unemployment fund	4/145 (3)	21/508 (4)	
Other	3/145 (2)	13/508 (3)	
Religion – no. (%)			0.098†
Do not believe in God	72/145 (50)	282/491 (57)	
Belief in God	73/145 (50)	209/491 (43)	

* Parents that stated having confronted the body at the site of the suicide. We asked "How did you find out that your child had died" and the answering alternatives were: found dead child, saw dead child at site but not as first person, notified in person, notified by telephone, other way. †Pearson's χ2 test. ‡Wilcoxon-Mann-Whitney's test.

Of the 666 suicide-bereaved parents that participated in the study, 109 had found the body of their child themselves, 32 had viewed the dead child at the scene of death but not as a first person, and 6 parents had witnessed the suicidal act. These parents constituted the 147 suicide-bereaved parents who were considered to be the exposed group. The rest of the suicide-bereaved parents that answered the question regarding the circumstances related to finding out about their child's death (N=512) constituted the non-exposed group. Among the non-exposed parents, 297 reported that they had been notified in person about the suicide of their child, 179 parents were notified by phone, 23 were notified in another way by someone else, 11 reported that they had been present at the hospital when their child died and 2 parents answered that they had been notified in another way but they did not leave any free-hand comment explaining how. Seven bereaved parents left this question in blank in their questionnaires which was considered as missing data (table 18).

Table 18. Circumstances related to finding out about child's death

Circumstances related to finding out about child's death	Suicide-bereaved parents (n=666)*
How did you find out that your child had died?	
Found dead child	109/666 (16)
Saw dead child at site of suicide but not as first person	32/666 (5)
Notified in person	297/666 (45)
Notified by telephone	179/666 (27)
Other way[†] - Received death notice from someone else	23/666 (4)
Other way[†] - Present at hospital when child died	11/666 (2)
Other way[†] - Witnessed the suicidal act	6/666 (1)
Other way[†] - no free-hand comment	2/666 (<0)
Missing	7/666 (1)

* Parents that lost a son or daughter to suicide, 2-5 years earlier. [†] 42 parents marked the response alternative "Other way" and 40 of them wrote free-hand comments that could be sorted into the four categories presented in this table

Concerning the circumstances related to the suicide, in general, the most common method of suicide was by hanging, strangulation or suffocation (52%) followed by poisoning using medication, chemicals or some kind of gas (15%) and leaping or laying in front of a moving vehicle (12%). Most of the exposed (64%) and non-exposed parents (57%) stated that they were not prepared for the suicide of their child. Viewing the body of the dead child in a formal setting such as at an emergency ward, at the hospital church, at the department of forensic medicine or at a funeral parlour, was more common in the exposed (78%) than in the non-exposed parents (67%). See Table 19.

Table 19. Circumstances related to the suicide of the child

Circumstances related to the suicide		**Suicide-bereaved parents**	
		Confronted body at the site of death[*]	Did not confront the body at the site of death
How did your child commit suicide			
Hanging, strangulation, suffocation	346/666 (52)	102/145 (70)	243/503 (48)
Poisoning[†]	101/666 (15)	27/145 (19)	73/503 (15)
Leaping or laying in front of moving vehicle	82/666 (12)	1/145 (1)	80/503 (16)
Jumping from a height	46/666 (7)	2/145 (1)	44/503 (9)
Discharging firearm	45/666 (7)	11/145 (8)	34/503 (7)
Crashing with car	10/666 (2)	0/145 (0)	10/503 (2)
Drowning	8/666 (1)	1/145 (1)	6/503 (1)
Cutting or stabbing	6/666 (1)	1/145 (1)	5/503 (1)
Other way[‡]	8/666 (1)	0/145 (0)	8/503 (2)
Missing	14/666 (2)	2	9
Where you prepared that your child might have committed suicide, when you found out that he or she was dead			
No	363/666 (55)	78/122 (64)	283/497 (57)
Yes, a little	88/666 (13)	17/122 (14)	71/497 (14)
Yes, moderately	33/666 (5)	4/122 (3)	29/497 (6)
Yes, much	138/666 (21)	23/122 (19)	114/497 (23)
Missing	44/666 (7)	25	15
Viewing the body in a formal setting[§]			
No	202/666 (30)	33/147 (22)	166/510 (33)
Yes	460/666 (69)	114/147 (78)	344/510 (67)
Missing	4/666 (1)	0	2

[*] Parents stated that they: discovered the dead body, saw the body at the site of death but not as the first person or had witnessed the suicidal act. [†]Poisoning for example by medication, chemicals or some kind of gas. [‡]Other way was according to the free-hand comments mainly related to burning oneself. [§]Parents that stated that they viewed their dead child in a formal setting. We asked if they viewed 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

6.4.1 Multivariable analysis

After performing a multivariable analysis, we found that confronting the body of the dead child was not associated with a statistically significant higher risk of reliving the child's death through nightmares (RR 0.95, 95% CI 0.67 to 1.35), intrusive memories (RR 0.97, 95% CI 0.84 to 1.13), avoidance of thoughts (RR 0.97, 95% CI 0.74 to 1.27), avoidance of places or things (RR 0.91, 95% CI 0.66 to 1.25), anxiety (RR 0.93, 95% CI 0.64 to 1.33) or depression (RR 0.94, 95% CI 0.63 to 1.42). See Table 19.

Table 19. Multivariable analysis

Psychological outcomes among the parents that confronted and did not confront the body at the death scene

Variables no. /total no. (%)	Confronted body at the site of death[*] n=147	Did not confront the body at the site of death n=512
Relived child’s death through nightmares the last month[†]	31/147 (21)	114/512 (22)
Relative Risk (95% CI)	0.95 (0.67 –1.35)	1.0 (reference)
Unadjusted odds ratios	0.93 (0·60 –1·46)	1.0 (reference)
Adjusted odds ratios[‡ § **]	1.01 (0·63 –1·63)	1.0 (reference)
Relived child’s death through intrusive memories the last month[†]	88/145 (61)	317/507 (63)
Relative Risk (95% CI)	0.97 (0·84 –1.12)	1.0 (reference)
Unadjusted odds ratios	0.93 (0·63 – 1.35)	1.0 (reference)
Adjusted odds ratios[‡ § ††]	0.97 (0.64 –1.48)	1.0 (reference)
Avoided thinking about things that reminds about child’s death the last month[†]	46/145 (32)	167/510 (33)
Relative Risk (95% CI)	0.97 (0.74 –1.27)	1.0 (reference)
Unadjusted odds ratios	0.95 (0.64 –1.42)	1.0 (reference)
Adjusted odds ratios[‡ § ‡‡]	0.90 (0.58 –1.39)	1.0 (reference)
Avoided things that reminds about child’s death the last month e.g. places and things[†]	35/144 (24)	136/507 (27)
Relative Risk (95% CI)	0.91 (0.66 – 1.25)	1.0 (reference)
Unadjusted odds ratios	0.88 (0.57 – 1.34)	1.0 (reference)
Adjusted odds ratios[‡ § § §]	0.96 (0.60 – 1.53)	1.0 (reference)
Depression (PHQ-9 score ≥ 10)[***]	24/143 (17)	90/505 (18)
Relative Risk (95% CI)	0.94 (0.62 to 1.42)	1.0 (reference)
Unadjusted odds ratios	0.93 (0.57 to 1.52)	1.0 (reference)
Adjusted odds ratios[‡ ††† ‡‡‡]	0.91 (0·52 to 1·60)	1.0 (reference)
Anxiety (GAD-2 score ≥ 2)[§ § §]	29/145 (20)	109/506 (22)
Relative Risk (95% CI)	0.93 (0.64 – 1.34)	1.0 (reference)
Unadjusted odds ratios	0.91 (0.58 – 1.44)	1.0 (reference)
Adjusted odds ratios[‡ ††† ****]	0.84 (0.50 – 1.41)	1.0 (reference)

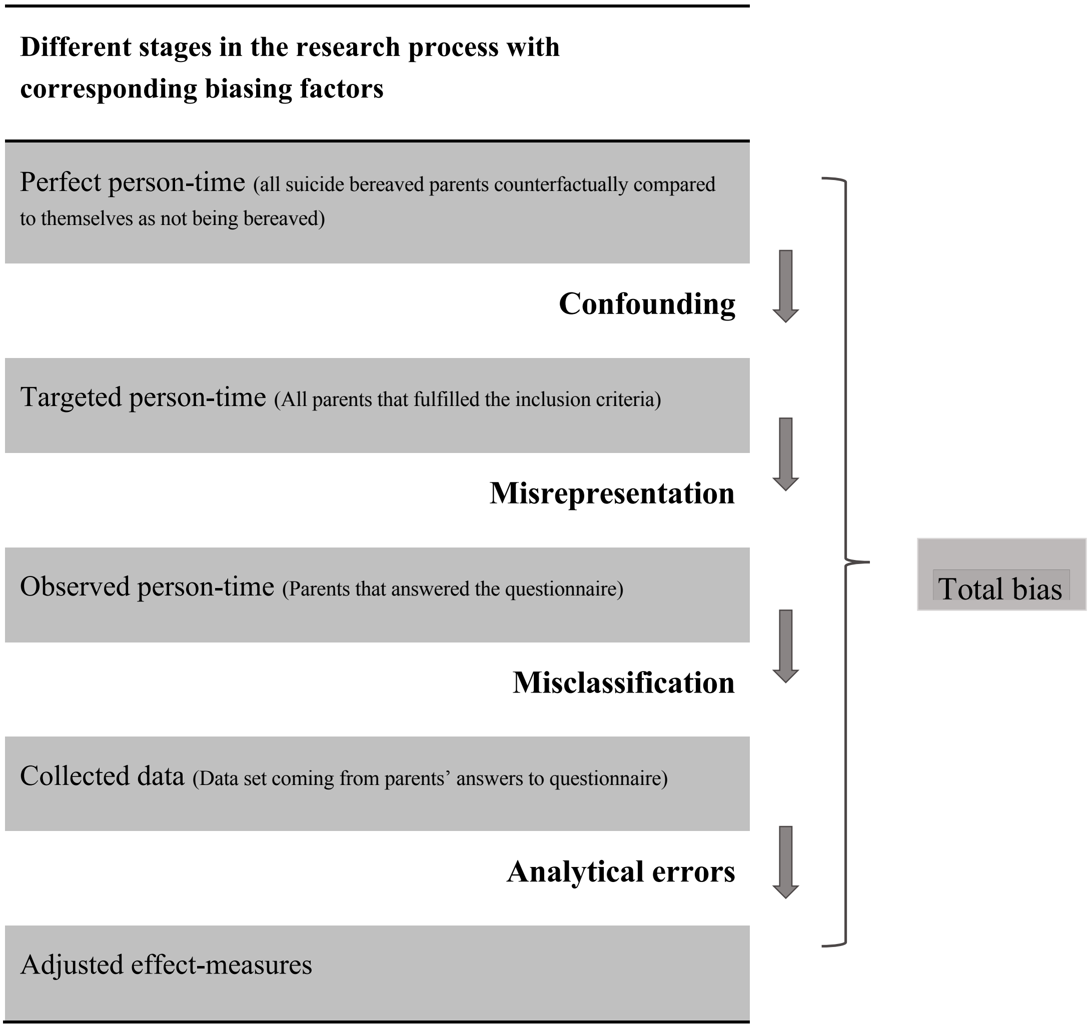
[*] Parents stated that they: discovered the dead body, saw the body at the site of death but not as the first person or had witnessed the suicidal act. [†] “No”,” Yes, occasionally”, “Yes, 1–3 days a week”, “Yes, 4–5 days a week”, “Yes, 6–7 days a week”. Dichotomized into “No” and “Yes”. [‡] OR adjusted for multiple variables selected by logistic regression forward selection (p<0.15). [§] Variables in the selection: sex, age, residence, civil status, income, education, physical activity, social activity, violent suicide, sleeping pill, anxiolytics, antidepressants, AUDIT, PHQ-9, and GAD-2. [**] Selected variables in selected order: GAD-2, sleeping pill, education, and sex. [††] Selected variables: GAD-2, sex, sleeping pill, physical activity, and residence. [‡‡] Selected variables: PHQ-9, social activity, sex, GAD-2, and age. [§ §] Selected variables: PHQ-9, sex, social activity, physical activity, GAD-2, 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, sleeping pill, anxiolytics, antidepressants and AUDIT. [‡‡‡] Selected variables: sex, AUDIT, income, social activity, age, physical activity, 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, AUDIT, social activity, age, physical activity, and civil status.

7 DISCUSSION

7.1 METHODOLOGICAL DISCUSSION

The perfect epidemiological study exists only in theory. As researchers, we want our results to be as close to reality as possible but there is no study that is free from errors. Two types of errors affect epidemiological studies: random error (chance) and systematic error (bias). Aiming to reduce the influence of systematic errors in the present study, we used Steineck's hierarchical step model for causation of bias to identify threats to validity in the design of the study, analysis and interpretation of data (Steineck et al., 2006). We started by considering the scenario of the "perfect study" also known as the counterfactual ideal (Rothman, 2002). Disregarding if we matched exposed individuals with similar unexposed individuals, these two groups may still differ in ways not considered by us. The ideal comparison between exposed and unexposed groups would include all suicide-bereaved parents in the world compared to themselves in the state of exposed and in the state of unexposed during the same period of time (Perfect person-time). If this could be done, we would be able to find out the exact effect of the exposure, since the only difference between these two settings would be the exposure. Since this situation is not attainable in reality, it is called counterfactual. We did our utmost to come as close to the counterfactual ideal as we could by identifying an unexposed population that was similar to the exposed population with the exception of the exposure. We then proceeded with different steps to identify potential biases in our study. According to the Steineck's hierarchical step model for causation of bias, each step in the research process introduces a source of systematic error, which we tried to reduce. See Figure 14.

Fig. 14. Steineck's hierarchical step model for causation of bias



7.1.1 CONFOUNDING

After considering what the "perfect study" would be, we strived to replicate this ideal situation as close as possible. We selected a group of persons to be studied (Targeted person-time) instead of including all suicide-bereaved parents in the world (Perfect person-time). In this way, we moved away from the Perfect person-time to the Targeted person-time. In this transition confounding was introduced. Confounding is a systematic error that leads to the introduction of bias in a study through the presence of a third variable which 1) Is associated with the exposure of interest and with the outcome, 2) Is unequally distributed between the exposure categories, and 3) Is not part of a causal chain (Rothman, 2002). The presence of a confounding factor causes an over or under-estimation of the true association between the exposure variable and the outcome variable. This is why researchers aim to prevent it or remove it (Rothman, 2002). Common methods to deal with confounding are randomization, matching and restriction. For obvious reasons we could not randomize participants to the exposure variable (the loss of a child to suicide) in this study. Instead, we tried to make the groups of comparison (bereaved and non-bereaved) as similar as possible (matching), with the exception of the exposure factor. In paper I, we described how careful consideration was given to the identification and inclusion of possible confounders when we designed our questionnaire. In our main quantitative study, bereaved and non-bereaved parents were matched for age, sex, area of residence, marital status, number of children and having a child of the same age as the deceased child. In paper II and IV we included various potential confounders, collected information about them and thereafter adjusted for them in the statistical analysis of the data.

7.1.2 MISREPRESENTATION

According to the Hierarchical step method for causation of bias, when we go from the Targeted person-time to the Observed person-time, we risk to introduce misrepresentation. Misrepresentation refers to the potential bias that occurs when the relationship between exposure and outcome differs between the intended study population (targeted person-time) and those who indeed participated in the study (observed person-time). Misrepresentation can occur when individuals decline participation or drop out from the study. When this happens, the study will lack information of a portion of the intended study population. Since there are virtually no statistical tools to deal with, for example, a high drop out rate, misrepresentation will inevitably affect the validity of the study. In order to minimize misrepresentation we planned the study carefully. We conducted a pilot study in order to test the logistics and to identify recruitment difficulties, and contacted those participants that did not returned their questionnaire during the stipulated time, in order to achieve their participation. Despite the sensitivity of the studied phenomenon, the large amount of questions included in our questionnaire and the fact that we made participation refusal easy, we received an unusually high participation rate (73% bereaved and 74% non-bereaved parents). Still, we do not know how the 27% of bereaved parents that did not participate differ from the parents who participated in the study. Among the non-participants, 18% of the bereaved and 5% of the non-bereaved parents explained their non-participation to be due to psychological distress or current illness.

7.1.3 Misclassification

Once we obtained the Observed person-time, collected information from participants gave rise to a data set. In this step, another threat to validity is introduced, namely misclassification. Misclassification refers to erroneously assigning individuals to the wrong category, either regarding the exposure (for instance, when a bereaved parent witnessed the suicide of his/her child and for some reason is classified as not having confronted the dead child), or the outcome (for instance, when a participant is classified as having low trust in the healthcare system when he/she actually trusts the healthcare system highly). Misclassification is a serious threat to validity if the errors are not equally distributed between the groups to be compared. Some ways to deal with misclassification are carefully planning the construction of the questionnaire, using validated research tools and, if possible, randomizing and blinding. Since we were unable to use randomization and blinding, we were especially careful in the formulation and validation of the study-specific questions and their corresponding response alternatives in our questionnaires, making sure that the questions measured what we intended to measure.

7.1.4 Analytical adjustments

In this final step we procured to reduce possible errors that were introduced in the previous steps. For this purpose, we used adjustment of the effect measures. In the first part of the study we formulated hypotheses taking into consideration possible effect modifiers, confounders, exposures and outcomes. We then dichotomized the values obtained from the questions to be included in our studies, such as level of trust in the healthcare system and the total scores of the psychometric scales. After this, we used log-binomial regression in order to calculate relative risks as effect measures. Once we obtained relative risks, we used logistic regression with forward selection in order to control for the variables that we had considered as possible confounders. In a multivariable model, the inclusion of several variables has as a consequence that each variable is controlled or unconfounded by the other variables included in the model (Rothman, 2012). In studies III and IV, the effect measure did not vary much after multivariable adjustments suggesting that from all the variables that we thought to be potential confounders none of them could account for our findings. Also, in study III we used multiple imputations to evade problems related to non-response. It is possible that there are some variables that could have explained our findings and that were not included in our study. From the theoretical frameworks that we used, we knew some of these variables but decided not to include them in our measurements. These known variables that may have influenced our findings but that we did not measure are, for example, family dynamics, personality, childhood psychological traumas, emotion regulation, and attachment style. We did not include these variables because the main goal of our studies was to improve the professional care of suicide-bereaved parents and siblings by identifying areas that might be of importance for this goal, thus our goal was not to research about suicide-bereavement as a process.

7.2 GENERAL DISCUSSION

7.2.1 Study I

The content of our study-specific questionnaire *was thoroughly validated.* We used four different means of validation: face to face validation, discussion of the answers to the questions and written comments with the participants, comparison of the information collected during the interview with the answers written in the questionnaire and comments from experts and clinicians about the content of the questionnaire. Our questionnaire *revealed to be feasible.* Despite the large amount of questions included and the presence of potentially distressing questions, the internal response rate was high. Altogether, the mean response rate was 98% for the main questions, probably implying that the questionnaire was not burdensome enough to make these parents withdraw their participation. Still, there were 109 bereaved parents that agreed to participate in the study but that did not return their answered questionnaires to us, which could indicate that they found it too burdensome. Another characteristic of our questionnaire is that *it was accepted by the participants*. We believe that the thorough validation process, the use of the parents' own ways to phrase their experiences when we created the questions, and the formulation of each question to measure only one conceptual entity and to be answered by choosing only one pre-defined response alternative were the reasons for this. Another characteristic is that the questionnaire *was pre-tested in our study population.* We performed a pilot study where we tested the questionnaire in a randomly selected group from our study population. In the pilot study we checked the appropriateness of the questions, tested the logistics and, specially, we made sure that the questionnaire did not cause harm to the participants (Kreicebergs, et al., 2004). It is sometimes considered that this kind of research is not possible to perform due to the belief that asking sensitive questions to potentially vulnerable populations will harm them. However, only a minority of participants (11% bereaved and 3% non-bereaved) stated that they had been negatively affected by the content of our questionnaire due to afflictive memories and distress. Only 2 participants out of 1043 thought that these negative effects would remain.

Why did we decide to create a new questionnaire? The reason why we created a questionnaire and did not make use of an existing psychometric instrument was that there is no validated scale that measures all our outcomes of interest that has been tested in a relevant study population. We followed the clinimetrics approach to measure health outcomes. Clinimetrics is the domain concerned with the measurement of not only symptoms but also the clinical phenomena around them (G. A. Fava, Tomba, & Sonino, 2012; Giovanni A. Fava & Belaise, 2005). Recent awareness of the inadequacy of only focusing on diagnosis of disease instead of focusing on the identification of modifiable factors makes clinimetric assessment vital since, among other, assesses impairment, distress and wellbeing rather than purely disease. Considering this, our questionnaire is not a psychometric instrument that provides a total score to show how much grief our study population has experienced. Instead, it was designed to compare outcomes between two groups of participants (exposed and unexposed) by using the same questions. The questions included in the questionnaire allow the testing of our research hypotheses in a nation-wide population survey. Our questionnaire also includes two psychometric scales to measure our main outcomes: depression (PHQ-9) and anxiety (GAD-2) and includes items that assess confounders and effect-modifiers (i.e. age, sex); exposures (i.e. confronting the body) and modifiable factors (i.e. physical activity, social activity).

What are the drawbacks of using a questionnaire like ours? There is not such a thing as "the perfect questionnaire". As researchers, we choose the means to obtain the answers to our research questions and that choice might imply some drawbacks in exchange of some advantages. With study-specific questionnaires, like the ones we used, we cannot fully compare our results with other studies of suicide-bereaved parents, with the exception of the measurement of depression and anxiety using the PHQ-9 and the GAD-2, respectively. There is also the possibility that this kind of questionnaires may not be sensitive enough to capture differences between groups concerning certain outcomes, like for example PTSD. We could probably have captured differences between the exposed and non-exposed groups (Study IV) if we had used a psychometric scale like the Impact of Event Scale (Horowitz, Wilner & Alvarez, 1979) or the Posttraumatic Diagnosis Scale (Foa, Cashman, Jaycox & Perry, 1997).

What are the benefits of using a questionnaire like ours? Our questionnaire enabled us to study variables of interest coming from our preliminary study with interviews to suicide-bereaved parents. For instance, in our preliminary study we identified phenomena surrounding bereaved parents receiving the death notification and confronting the body, phenomena which were identified as important but for which there are no psychometric instruments that have been used in suicide-bereaved population-based surveys. Researchers in suicidology recommend a more complex assessment to improve the scientific quality of the data (Pitman, Osborn, King, & Erlangsen, 2014). The broader understanding, that in this way we achieve, allows us to observe, the often very diverse and complex reality that bereaved persons experience.

Experiences such as health, wellbeing and trust, are subjective. The subjective rating of the individual's own health through a single item has been found to be the best predictor of mortality even after controlling for age, gender and socio-economic status (Burström & Fredlund, 2001; DeSalvo, Bloser, Reynolds, He, & Muntner, 2006; Idler, Russell, & Davis, 2000). In our studies, instead of assessing the participants' wellbeing using only standardized criteria for what health is, we used single item questions leaving to the individuals themselves to value their experience of health in relation to their own life situation and personal goals. From this perspective, health is not just the absence of disease but something more complex. We think along the lines of Huber et al., (2011), who propose health to be defined as "The ability to adapt and self manage in the face of social, physical and emotional challenges" and the WHO definition of mental health (2005) "Mental health is a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stressors of life, can work productively and is able to make a contribution to his or her community."

7.2.2 Study II

A few years ago, Norwegian researchers called attention upon the urgent need of qualitative studies in suicidology, since publications in this field mainly used the quantitative approach. They argued that to bring the field forward, studies in suicidology should not only focus on finding *explanations* – hypothesis-deductive or experimental methodology, but also they should focus on *understanding* – and aim to perform pure qualitative studies or studies that use a combination of quantitative and qualitative methodologies (Hjelmeland & Knizek, 2010). This is one of the reasons why we performed a qualitative study based on 18 interviews with suicide-bereaved siblings in Sweden.

The initial aim in this part of the research project was to collect qualitative data in order to create a study-specific questionnaire that would help us to investigate areas or interest in order to improve the care provided to suicide-bereaved siblings. We did not choose ethnographic methodology since we were not aiming to understand the culture that the suicide-bereaved siblings share over extended periods of time (Kvale & Brinkmann, 2009). We did not consider it appropriate to use grounded theory either, since we did not aim at theory development (Kvale & Brinkmann, 2009). The type of qualitative data analysis that we chose was content analysis because we wanted to obtain a broad description of the studied phenomenon in categories that describe the phenomenon.

Most suicide-bereaved siblings want professional help but not all of them seek it. Most of the interviewed bereaved siblings reported their wish and need of professional help, but not all of them had actively sought it. Reasons for not seeking professional help were that they did not trust the health services' capability to provide support and were so stricken by their grief that they did not have the emotional and physical strength to seek help. These findings are largely in line with previous studies (McMenamy et al., 2008; Wilson & Marshall, 2010) but our unique contribution is that we did not include and mix different kinships. We studied professional help-seeking behavior after the suicide of a relative in a population consisting only of siblings.

The deceased siblings' experiences with health services became a point of reference that kept the bereaved siblings from seeking professional help. The suicide-bereaved siblings' help-seeking behavior and attitudes towards health services were influenced by the perception of their deceased sibling's experiences with health services. To the best of our knowledge, there are no previous publications regarding the impact of negative perceptions of the professional help that the deceased relative received on the help-seeking behavior in the suicide-bereaved. Nevertheless, there are studies that show that previous experiences with health services are facilitators that lead individuals to seek professional help (Gulliver, Griffiths, & Christensen, 2010; Komiti, Judd, & Jackson, 2006). The unmet needs of the deceased sibling were only mentioned by those participants who had sought professional help and were dissatisfied with the help they received. However, when the bereaved siblings had been encountered by health professionals whom they judged as empathic, competent and easily accessible, they did not refer to the unmet needs of the deceased sibling. Unfortunately, it is impossible to undo previous own or the sibling's negative experiences with the health services but probably, the quality of the professional encounter that suicide-bereaved siblings are exposed to when they approach health services to ask for help, can probably make a difference in their attitudes towards health services. This area needs to be further studied.

The deceased siblings' recommendations to health services. We did not want the bereaved siblings to tell us what they had heard or read concerning what suicide-bereaved siblings need from health professionals. Instead, we wanted them to base their recommendations on their own experiences. With the formulation and inclusion of the question "What would you recommend health services to do when encountering suicide-bereaved siblings in the future?" we made sure that these recommendations were personal and experience-based. This question gave rise to lively personal narratives that provided us with a deep insight into their perceived needs and their recommendations to health professionals. Immediate, outreaching and repeated contact; qualified professionals; provision of information, help to understand the reason for the suicide, and help to cope with grief feelings are in summary the recommendations of the deceased siblings to health service providers. These recommendations go in line with previous studies (K. Dyregrov, 2002b, 2009; J R Jordan, 2001).

Methodological considerations

Relevance. We consider that our present study contributes to the current knowledge of professional help-seeking behavior in suicide-bereaved siblings. Our finding that perceived suboptimal care of the deceased sibling may contribute to the development of negative attitudes and low expectations of the helpfulness of health services in suicide-bereaved siblings is unique and important. We observed that negative attitudes towards health services may reduce the likelihood of seeking professional help as well as the acceptance of medication in some cases.

Organization of our findings. We chose to organize our findings according to our research questions for clarity reasons. Another way to organize the findings would have been into "barriers" and "facilitators" for seeking professional help. Since the organization of health services varies substantially across countries, and the Swedish healthcare system is tax-funded and universally provided, what is a barrier or facilitator here may not be such in healthcare systems organized and financed in ways different from the Swedish healthcare system.

Sampling. It should be recognized that this qualitative study included a small number of participants. However, in qualitative research, frequencies are seldom important. One occurrence of the experience is potentially as useful as many experiences when researchers aim to understand the process behind a phenomenon. Sample size in qualitative studies depends on the research aim. Adequate sample size is that, which in its quality of not being too long, allows deep, case oriented analysis, and in its quality of not being too small, allows rich understanding of the experience under study (Sandelowski, 1995). The size of our sample was determined by *saturation*, meaning the point in data collection when no new or relevant information emerges from the interviews (Given, L., 2008). Probably, a bigger sample would have allowed us to compare our findings by years since loss, sex, place of residence, etcetera. However, that was not the aim of this paper.

Representativeness. Even though participants came from different parts of Sweden and constituted a heterogeneous group, we cannot claim that they are representative of all the suicide-bereaved siblings in Sweden. The voluntary nature of our recruitment made participation limited to those individuals who actually were willing and able to share their experiences and express their views with us at that point in time. Furthermore, despite the fact that the interviews from this group produced copious and relevant material, the one-to-one setting of the interviews may have suppressed certain experiences and opinions that other settings used in qualitative research may have promoted (i.e. focus groups). Consequently, it is conceivable that other important experiences may exist both, among the siblings who participated and among all the others who did not participate. However, our findings have raised issues for consideration and themes of relevance in relation to the phenomenon of losing a sibling to suicide.

Trustworthiness. In order to assure *credibility* we used multiple coders where categories and main themes were assigned by the first author and then reviewed by two co-authors assuring unbiased data analysis and interpretation of results. In this way, we strived to make sure that all relevant data was indeed included (Graneheim & Lundman, 2004). *Confirmability* was addressed through the discussion section, using constant reference to previous research that supports our findings. To show that our findings were shaped by the content of the interviews and not by the researchers' motivation or bias, in the article, we present quotes so that the reader can follow the construction of findings. Still, my psychological background as the interviewer and the psychiatric/medical background of my co-authors may have influenced the direction of the interviews and the interpretation of findings. Also, we could have applied triangulation using different types of data (qualitative and quantitative) and different methods (ex. observations and interviews) to see if they confirm each other (Silverman, 2010). Regarding generalization of findings, qualitative methodologists recommend "thick" descriptions in qualitative studies, referring to providing the reader with a thorough description of the study setting, participants and observed processes (Polit & Beck, 2010). To increase *transferability* we provided a thorough description of the participants' characteristics and the Swedish context, including the available help for the suicide-bereaved in Sweden. Also, we advised the readers to consider the type of health system existing in Sweden, where healthcare is government administrated, tax-financed, universally provided and patients pay only a minimal nominal fee. In addition, we described in detail our research questions and the method we used for data analysis. From here, readers and science consumers will judge if our findings can be extrapolated to their own contexts. Generalizability of findings can be achieved through successful replication (Polit & Beck, 2010). If our findings can be confirmed in other contexts their validity and applicability will be reinforced.

We should also consider that participants were interviewed only once. Another way to design this study could have been as a longitudinal qualitative research, interviewing the participants at various occasions along time. However, the observation of changes over time and the maturation in the perception of health services after the suicide of a sibling was not our main goal with the interviews, instead we wanted to create a questionnaire for suicide-bereaved siblings for a future national study. Apart from this, a longitudinal design would have needed larger samples to counterbalance attrition and also long-term financial funding, which we did not have.

7.2.3 Study III

A big criticism of research in suicide-bereaved individuals is the methodological shortcomings of certain studies such as small sample sizes, selective and non-representative samples – i.e. recruitment of participants through health providers – low participation rates, and a mixture of different kinship. Furthermore, controlling for potential confounding effects of pre-bereavement psychopathology is considered as an essential building block for high quality research in the suicide-bereaved (Pitman et al., 2014). We therefore performed a nation-wide population-based survey of suicide-bereaved parents. In study III, we found that lack of trust in the healthcare system was more prevalent in suicide-bereaved parents (47%) than in non-bereaved parents (18%). Considering only the bereaved parents, the variables that we found to be associated with lack of trust in the healthcare system were: having high scores of current depression as measured by the PHQ-9, living in big cities (>200,000 inhabitants) and being single.

To the best of our knowledge, this is the first large study concerning suicide-bereaved relatives' trust in the healthcare system. However, our findings resonate with those of an American study of 71 suicide-survivors, which included mixed kinship (relatives and friends). These participants answered a survey including included an open-ended question asking the respondents to describe how their attitudes and/or beliefs towards mental healthcare had changed after their loss. Nineteen of the 51 participants who answered this question reported having "Lack of faith in clinicians/mental healthcare system", making it the most common answer (Peterson, Luoma, & Dunne, 2002).

Place of residence is associated with lack of trust in the healthcare system in suicide-bereaved parents. Considering only the suicide-bereaved parents, we found that the more populous the city, the higher their lack of trust in the healthcare system. Haven et al. studied health confidence in rural, suburban and urban areas in the general population in the USA (n=2501) and the UK (n=1511) (Haven, Celaya, Pierson, Weisskopf, & Mackinnon, 2013). They measured health confidence by asking the participants about their confidence in receiving effective treatment and confidence in being able to afford the treatment. The researchers found that lack of confidence in receiving effective treatment increased according to population size, with that the percentage of "Not very confident" or "Not at all confident" residents being: in rural areas 15%, sub-urban areas 18% and urban areas 21% (p=0.004). This study was not performed on suicide-bereaved individuals and we did not observe this trend in the non-bereaved parents. However, it is possible that specific factors present in urban areas may have contributed to lower trust in the healthcare system among the suicide-bereaved parents. This could be due to the fact that urban environments are associated with higher prevalence of psychopathology and higher comorbidity rates in comparison to rural areas (J. Peen, Schoevers, Beekman, & Dekker, 2010; Jaap Peen et al., 2007). Also, people living in rural areas show better self-perceived health than people living in urban areas (Maas, Verheij, Groenewegen, de Vries, & Spreeuwenberg, 2006). We can speculate that, probably in conjunction with these factors, the perception of more psychological distress, lower sense of community, more socioeconomic disparities and higher expectations in the quality of care, contribute to a higher lack of trust in the healthcare system in suicide-bereaved parents living in urban areas. However, we did not find any impact of the size of place of residence in the levels of trust in the healthcare system in the non-bereaved parents. This may be because the Swedish population, in general, is very trustful of their institutions and others (Morrone et al., 2009). Presumably, this high trust in the healthcare system is breached when one loses a child to suicide in Sweden.

Marital status is associated with lack of trust in the healthcare system in suicide-bereaved parents. We found that bereaved single parents presented more lack of trust in the healthcare system than bereaved parents who lived with a partner or were in a relationship. However, we did not we find any difference between bereaved parents living with a partner and bereaved parents who were widows/widowers. Probably, in addition to the day-to-day difficulties of raising a psychologically vulnerable child alone, bereaved single parents may have experienced additional stressors such as economic disadvantages, social stress (Targosz et al., 2003) and difficult interactions with governmental institutions (Butler, McArthur, Thomson, & Winkworth, 2012; McArthur, Thomson, & Winkworth, 2013). This may in turn have decreased their trust in governmental institutions including the healthcare system. We did not find previous research regarding marital status and lack of trust in the healthcare system in the aftermath of a suicide-loss. Still, there are studies that show an association between the condition of singlehood in bereaved parents and negative grief outcomes. For example, Ostfeld et al. (1993) studied grief after sudden infant death syndrome in mothers (n=38). The mothers self-rated their initial and present grief six months after their children's death. The researchers found that married mothers had significantly lower grief scores than single mothers shortly after the loss and also to a greater extent at six months after the loss. Married mothers were also more likely to attend support groups than single mothers (Ostfeld, Ryan, Hiatt, & Hegyi, 1993). We did not find previous studies concerning marital status and lack of trust in the healthcare system in bereaved populations. We can only speculate about the mechanism behind this association between marital status and lack of trust in the healthcare system in our study. Ahnquist et al. (2010), investigated levels of trust in the healthcare system in 56 889 randomly selected individuals in Sweden. They observed that low trust in the healthcare system was associated with 59%-fold increased risk for psychological distress among men and 83% among women. We can speculate that suicide-bereaved single parents receive less social support and experience more emotional isolation than their married counterparts. These difficulties may increase their levels of psychological distress, which in turn may influence their trust in the healthcare system. This is a phenomenon that needs further research. We observed no difference in levels of trust in the healthcare system between bereaved parents living with a partner and bereaved parents who were widows/widowers. This could be due to the fact that widows/widowers have had a partner for a certain period in their lives and this may have regulated the effect of singlehood on lack of trust. This is a phenomenon for further study.

Depression is associated with lack of trust in the healthcare system in suicide-bereaved parents. We observed that despite excluding parents with psychiatric morbidity of 10 or more years ago, currently depressed parents were still the most distrustful of the healthcare system, whether bereaved or non-bereaved. This association had a dose response where the higher the level of depression, the higher the level of lack of trust in the healthcare system in both, bereaved and non-bereaved parents. The finding of Ahnquist et al (2010) regarding the association between psychological distress and lack of trust in the healthcare system indirectly supports our finding since depression is an indicator of psychological distress. The instrument these researchers used to measure psychological distress, the General Health Questionnaire (GHQ-12), includes items that are indicative of depression such as “Have you felt unhappy and depressed during the past weeks?”, “Have you felt worthless during the past weeks?”, and “Have you had problems with your sleep during the past weeks?”

Disappointment with the care provided to the child and lack of trust in the healthcare system. The association between being suicide-bereaved and lacking trust in the healthcare system may to some extent occur as a consequence of being disappointed in the quality of the care provided to the child. Parents who reported moderate to much disappointment with the healthcare their child received, presented more lack of trust in the healthcare system (71%), than parents who reported little to no disappointment (21%). Parents who reported that their child had not been in contact with the healthcare system reported lack of trust in the healthcare system (31%). Previous research has identified disappointment with health services as a key theme in the analysis of narratives of ten suicide-bereaved relatives. Their disappointment was related to feeling that their concerns about their relative’s imminent suicide risk were not taken seriously by health services (Peters, Murphy, & Jackson, 2013).

We do not know if the bereaved parents trusted or did not trust the healthcare system before losing a child to suicide. Still, we know that the Swedish population ranks as a one of the countries with the highest institutional and interpersonal trust worldwide (Morrone et al., 2009). Probably, for those parents that trusted the healthcare system before their child’s suicide, losing trust might be a reflection of shattered assumptions of the benevolence and safety of the world (Janoff-Bulman, R., 1989). An unmeasured variable that could have influenced our results is prolonged grief. However, since prolonged grief disorder was not set to be a main outcome when we planned our project, we have not measured it and therefore we did not control for an association between the lack of trust in the healthcare system, that we found in the suicide-bereaved parents, and prolonged grief disorder. This is a phenomenon for further study. Also, we used matched non-bereaved parents as comparison group. We did not use parents bereaved by other types of death. It remains to be studied if our results regarding lack of trust in the healthcare system are specific to suicide bereavement or if they are also found in other bereaved populations such as parents who have lost a child due to accidents, drug overdoses or natural causes of death. With the question used in this study: “Do you trust the Swedish healthcare system today?”, we obtained a global measure of trust in the healthcare system. We did not obtain fine-grained information concerning which areas, aspects or actors within the healthcare system are the subject of lack of trust for bereaved parents. Furthermore, it is possible that the bereaved parents also lost trust in other public institutions, such as the legal, educational and political systems. These areas need further study.

7.2.4 Study IV

To the best of our knowledge, this is the first population-based survey on bereaved parents aiming to elucidate the psychological impact of confronting the body of a child, deceased by suicide, at the scene of death. In contrast to our hypothesis, we found no statistically significant difference between bereaved parents who had confronted the body of their deceased child, and those who had not (2-5 years after the loss) concerning reliving the child's death in nightmares, experiencing intrusive memories, or avoiding thoughts, places or things related to the suicide. Also, we did not find any difference regarding the levels of depression or anxiety between these two groups.

A possible explanation for the lack of differences in the studied psychological outcomes between parents that confronted the body of their child and parents that did not, is that the effects of the exposure may have been equaled out between the two groups. Currently, there are therapeutic techniques and self-help methods that people can use in order to cope with PTSD symptoms (Lewis, C. et al., 2013) and to reduce symptoms of depression and anxiety (Edenfield, T & Saeed, SA, 2012). It is possible, if the exposed group of bereaved parents received help in this domain, that this help may have reduced the measured outcomes to the level of the non-exposed group. On the other hand, the prevalence of the studied outcomes may have been raised in the non-exposed group through other aspects of the loss that were not included in this study, for example, the psychological impact of the death notification and emotion regulation.

Sudden losses can make it difficult for the bereaved to grasp the reality of their loved one's death and confrontation with the reality of the loss may not always translate into negative health outcomes in the bereaved relatives. Jabre et al (2014) found that relatives present at cardiopulmonary resuscitation presented fewer bereavement-related symptoms of PTSD, depression and traumatic grief in comparison to relatives that were not present. In our study, parents who witnessed the suicide or found their child's body at the site of the suicide were immediately confronted with the reality of the death. It is reasonable to believe that, this experience provided the exposed group of parents with a fuller understanding of what had happened, helped them to organize the loss along a timeline, and to structure facts into a coherent narrative facilitating their grief process (Harrington, 2012). Also, parents that had not viewed the body may have re-enacted the death of their child in their minds achieving the same levels of distress as the parents who confronted the body (Chapple & Ziebland, 2010).

Our results do not support our hypothesis that parents that confront the body of their child, dead by suicide, present higher prevalence of psychological distress than parents that do not confront the body. However, our results do not in any way demean or deny the enormous grief experienced by the parents who confronted the body of their child. What we observed is that viewers and non-viewers presented similar levels of psychological outcomes and that these responses may not be only determined by external circumstances. Further study is necessary before clinical implications can be drawn.

One of the strengths of this study is that it included a large population of unselected suicide-bereaved parents, which was retrieved from high quality registers. Also, the participation rate was high among male and female participants and almost all of them answered the study specific question that we used in this study (659/666). However, it should be recognized that, we do no have information regarding the suicide-bereaved parents that did not return their questionnaire to us, in this way not participating in the study. Probably, many of the parents that did not participate in the study had high levels of psychological distress. We do not know if non-participants had discovered the body, had seen it but not as a first person, or if they had witnessed the suicide of their child. It could be that the incidence of bereaved parents that confronted the body of their dead child was big in non-participants.

Probably, the psychological outcomes in the exposed and non-exposed groups do differ when using measures that were not considered by us. For instance, in this study we did not include a psychometric measurement of complicated grief or a full assessment of PTSD. Moreover, our questionnaire did not include internal factors that may be related to the grief process like personality and coping styles. Therefore these factors were not included in this study. Also, the bereaved parents answered the questionnaire 2-5 years after their loss. We do not know if the psychological outcomes included in this study differed between parents that confronted the body of their child and parents that did not, outside this time span. Furthermore, the fact that the participants answered the questionnaire 2-5 years after the suicide of their child may have compromised the parents' accuracy to recall the events surrounding their child's suicide. However, we think that recall-induced bias is minimal since the outcome measures of psychological distress correspond to how the parents answered that they were feeling the last month or the last two weeks.

8 CONCLUSIONS

Study I showed that suicide-bereaved parents may indeed participate in research studies and answer sensitive questions provided that these questions are included in a thoroughly constructed questionnaire, which involves the bereaved parents' participation from the beginning and also, as long as the research process follows robust ethical and methodological procedures.

Study II showed that suicide-bereaved siblings who perceive that the professional care provided to their deceased sibling was sub-optimal may develop negative attitudes towards health services and that they may present low expectations regarding the helpfulness of health services. In turn, these negative attitudes and low expectations may reduce the likelihood of seeking professional help and medication acceptance in the bereaved siblings.

Factors that contribute to the bereaved siblings' satisfaction when receiving professional help are: easy availability and health professionals who are qualified and empathic. The bereaved siblings' experience-based recommendations to health professionals are the establishment of contact, assessment of anxiety and sensitivity to their family concerns.

Study III revealed that lack of trust in the healthcare system is significantly more prevalent in suicide-bereaved parents than in non-bereaved parents. Moreover, suicide-bereaved parents' lack of trust is associated with living in big cities, having high scores of depression as measured by the PHQ-9, and being single.

This is the first study of trust in the healthcare system in a nation-wide population of only suicide-bereaved parents. In the general population, lack of trust in the healthcare system has been associated with negative outcomes such as increased risk of psychological distress, low self-rated health, increased risk for daily smoking and not undergoing screening for life threatening diseases.

Study IV found no support for the stance that confronting the body of the dead child at the scene of the suicide increases the risk of negative psychological outcomes in parents two to five years after the suicide of their child.

This is the first large population-based survey to investigate psychological outcomes in parents who confront the body of their child after his/her suicide. This study needs to be replicated ideally using a longitudinal design.

9 FUTURE PERSPECTIVES

- Research has shown that men and women cope with bereavement differently (Schut, Stroebe, van den Bout, & de Keijser, 1997; M. Stroebe, 2001). This fact raises the question: Are there differences in help-seeking behavior in women and men after the suicide of a child or a sibling? Future studies including a large, representative and unselected sample of suicide-bereaved relatives may benefit from investigating these differences.

- We do not know for how long suicide-bereaved siblings' negative attitudes towards health services prevail over time and, if these negative attitudes can be changed. Interventional strategies that take into account the siblings' recommendations to health providers may improve their view on the helpfulness of health services. This area needs further investigation.

- Future research would benefit from studying to what extent negative attitudes towards health services translate into non-help seeking behavior in suicide-bereaved individuals.

- Our study of suicide-bereaved siblings is part of the preliminary phase of a population-based, nation-wide survey, which will be performed by our research group in the near future. The questionnaires to be sent to the bereaved and non-bereaved siblings have already been constructed. A measure for consideration would be to send the questionnaires through the Internet instead of a paper booklet, since this is a younger population that is very acquainted with electronic formats. The study of suicide-bereaved siblings will not only provide us with a deeper understanding of the impact of losing a sibling to suicide but will also allow us to observe if there are differences in outcomes between bereaved siblings and parents (i.e. confronting the body, trust in the healthcare system).

- Another topic for further study would be if lack of trust in the healthcare system in suicide-bereaved parents is a reflection of prolonged grief disorder. Criteria sets proposed for the inclusion of prolonged grief disorder in the DSM-V consider the individual's trust in others as a criterion for the diagnosis of this disorder:

  - The criteria for Prolonged Grief Disorder (Prigerson et al., 2009) include, under cognitive, behavioral and emotional symptoms, the criterion "Inability to trust others since the loss."

  - The criteria for Complicated Grief (Shear et al, 2011) include the criterion "Persisting difficulty trusting or caring about other people or feeling intensely envious of others who have not experienced a similar loss."

  - The criteria for Adjustment Disorder Related to Bereavement and Bereavement Related Disorders, proposed to be included in the DSM-V by the Anxiety Disorder Working Group (APA, 2012), include the item “Difficulty trusting others since the death.”

- After finding that suicide-bereaved parents do not trust the healthcare system, a very important question is: Can we, health professionals, restore their trust in the healthcare system? How?

10 SVENSKT ABSTRAKT

Bakgrund

Att förlora ett barn i självmord är en överväldigande upplevelse som ökar risken för negativa hälsoeffekter för sörjande föräldrar och syskon, såsom långvarig psykiatrisk sjuklighet och ökad risk för förtida dödlighet, inklusive självmord. Trots deras behov och den ökade risken för sorg svårigheter relaterade till sorgen, är kunskapen om vilken vård som är effektiv för att förebygga svårigheter begränsad och det saknas populationsbaserade studier som undersöker detta. Det främsta syftet med våra studier är att förbättra den professionella vården av suiciddrabbade föräldrar och syskon genom att utforska några intresseområden som kan ses som ett första steg mot detta mål.

Metoder

Vi förfinade våra arbetshypoteser, skapade ett studie-specifik frågeformulär, validerade och testade det, inklusive datainsamlingsprocedurer (Studie I). Dessutom intervjuade vi 18 suiciddrabbade syskon och analyserade deras berättelser kvalitativt bland annat deras uppfattning om sjukvården (studie II). Med hjälp av vår studie specifika frågeformulär undersökte vi förekomsten av och variabler associerade till bristande förtroende för sjukvården i en population av 666 suiciddrabbade och 326 icke-förlustdrabbade föräldrar (studie III). Vi undersökte också de psykologiska effekterna av att konfrontera kroppen av det avlidne barnet på platsen för självmordet hos de drabbade föräldrarna (studie IV).

Resultat

Av de 46 suiciddrabbade föräldrar som besvarade frågeformuläret i vår förstudie, 45 ansåg att studien var värdefullt och 24 svarade att de hade påverkats positivt av att besvara på enkäten, medan 3 hade påverkats negativt. En majoritet uppgav att de var tacksamma för möjligheten att berätta om sina erfarenheter kring barnets död (studie I). Vi fann också att de flesta suiciddrabbade syskon hade önskat professionell hjälp, men att manga inte sökte hjälp på grund av bristande förtroende för sjukvården eller för att de upplevt en överväldigande sorg. En minoritet uppgav att de inte hade haft behov av professionell hjälp. Det avlidna syskonets erfarenhet av sjukvården blev en referenspunkt som påverkade de sörjande syskonens uppfattning om sjukvårdens möjlighet att hjälpa (studie II). Vidare fann vi att brist på förtroende för sjukvården var vanligare hos föräldrar som mist ett barn i suicid (47%), jämfört med föräldrar som inte hade mist ett barn (18%), vilket resulterade i en relativ risk på 2,5 (95% KI 2,0 - 3,3). Bland de förlustdrabbade föräldrarna, var brist på förtroende för sjukvården associerat till att vara deprimerad, mätt genom Patient Health Questionnaire (PHQ-9), att bo i storstäder (> 200.000 invånare) och att vara singel (studie III). I studie IV, fann vi att erfarenheten av att konfronteras med det döda barnet på platsen för självmordet inte var associerat med en statistiskt signifikant högre risk att återuppleva barnets död genom mardrömmar (RR 0,95, 95% CI 0,67-1,35), påträngande minnen (RR 0,97, 95% CI 0,84-1,13), undvikande av tankar (RR 0,97, 95% CI 0,74-1,27), undvikande av platser eller saker (RR 0,91, 95% CI 0,66-1,25), ångest (RR 0,93, 95% CI

0,64-1,33) eller depression (RR 0,94, 95% CI 0,63-1,42) när man jämförde föräldrar som hade den erfarenheten med dem som inte hade den.

Slutsatser

Föräldrar som mist ett barn I suicid kan delta i forskningsstudier som inkluderar känsliga frågor, så länge forskningsprocessen följer robusta etiska och metodologiska förfaranden (Studie I). Syskon som har mist en bror eller syster i suicid och vars uppfattning är att den vård som gavs till det avlidne syskonet var bristfällig, kan ha en negativ attityd till sjukvården och låga förväntningar på sjukvårdens möjlighet att hjälpa (studie II). Prevalensen av bristande förtroende för sjukvården var högre bland föräldrar som mist ett barn i suicid än hos föräldrar som inte mist ett barn. Deras brist på förtroende befanns vara förknippad med att vara deprimerad, att bo i en storstad och att vara singel (studie III). När det gäller den psykologiska effekten av att se sitt döda barn på platsen för självmordet, fann vi inga signifikanta statistiska skillnader mellan föräldrar som konfronterats med kroppen av det avlidna barnet och de som inte gjorde det (studie IV).

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